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Recovery in Borderline Personality Disorder: A Mixed-Methods Exploration of Lived Experience

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Recovery in Borderline Personality Disorder: A Mixed-Methods Exploration of Lived Experience

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CERTIFICATION

I, Fiona Yum Yu Ng, declare that this thesis, submitted in fulfilment of the requirements for the award of Doctor of Philosophy (Psychology), in the School of Psychology, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. This document has not been submitted for qualifications at any other academic institution.

Fiona Yum Yu Ng

June 2019

ABSTRACT

Background: Understanding of recovery in mental health has evolved to include clinical definitions and personal recovery models. However, knowledge surrounding personal recovery have been predominately derived from qualitative studies of individuals with severe mental illness such as psychosis. This thesis by compilation presents four studies which explored the concept of personal recovery in the context of Borderline Personality Disorder (BPD) to describe the lived experience of recovery.

Method: The thesis provides an introduction to the literature (Chapter One) and the methodology undertaken in the research (Chapter Two). The research consists of five components. Firstly, a systematic review (19 studies representing 1122 individuals) to examine the current state of the literature and identify gaps to guide the direction of the thesis (Chapter Three). Chapter Four presents archival data from clinical interviews to identify the treatment and recovery goals of individuals seeking treatment for BPD. Chapter Five presents a mixed-methods study which uses bivariate and multivariate analysis to examine the role of an individual's self-identified recovery status and diagnostic status on clinical and personal recovery outcomes in 349 individuals who completed an online survey. To further understand one's self-identified recovery status, thematic analysis was conducted on individual's personal definition of recovery in BPD. Chapter Six draws upon data from participants in Chapter Five and consists of an interpretative phenomenological analysis of 14 in-depth interviews investigating recovery stages and processes in individuals at opposite ends of the recovery continuum.

Results: Of the 19 studies in the systematic review, only three examined personal (versus clinical) recovery through the perspective of people with lived experience of BPD (Chapter Three). Whilst treatment and recovery goals of individuals seeking treatment for BPD

indicate that symptom reduction was an important goal, 88.2% of individuals reported goals of a psychosocial nature, indicating that goals extend beyond clinical realms (Chapter Four). The importance of an individual's evaluation of progress and personal definition of recovery was highlighted by findings that individuals who self-identified with being recovered, regardless of whether they met diagnostic criteria, did not differ on clinical or personal recovery outcomes. Definitions of recovery in BPD was seen to take on two definitions; recovery as self-management or recovery as not possible (Chapter Five). Identification of the stages and processes of recovery identified that recovery occurred across three stages and involved four processes, with the interaction between stages and processes promoting change (Chapter Six).

Conclusion: Taken together, the research has provided evidence to broaden recovery perspectives of individuals with BPD to be more personally meaningful and provides recommendations for how services and treatment incorporate more recovery-focused goals.

ACKNOWLEDGEMENTS

The saying ‘it takes a village to raise a child’ goes a long way in writing a PhD thesis. This thesis was the ‘raised’ from numerous hours of sweat, laughter and tears and would not have been possible without the support of the following villagers.

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To all my friends and colleagues who celebrated/commiserated/laughed/cried with me throughout the PhD journey. This journey would not have been as rich, intellectually stimulating or fun without you all. I am so grateful that I have met each of you and cheers to the next chapter of our friendship. In no particular order: Rebecca Campbell, Stanley Lam, Taneile Kitchingman, Johanna Meyer, Haidar Catan, Camilla Beale, Briony Osborn, Annette Oertle, Arina Baharin, Gamze Abramov, Kate Lewis, Annaleise Gray, Nick Day, Denise Meudijk, Caitlin Miller, Cella Jusuf, Phoebe Chin, Isabelle Wong, Juliet Zhu, Leigh Wilson, Melanie Keep, and Nashwa Ibrahim.

To my family, Mum, Dad and Anna. Thank you for always supporting and encouraging me to chase my dreams – even when that meant moving to the other side of the world. No matter the time of day (or night), you were there to listen to all my tales and to console me when times were tough. I am forever grateful for your love and support, I couldn't have done it without you.

STYLE OF THESIS STATEMENT

This thesis has been prepared in accordance to the University of Wollongong guidelines for 'Thesis by Compilation' (Ralph, 2017). This thesis is presented as seven chapters and consists of published journal articles or articles under review.

Chapter One: *Introduction* presents an introduction to the thesis and an overview of the research topic. It describes the objectives and significance of this research, whilst outlining the format of this thesis by compilation.

Chapter Two: *Method* presents the methodology adopted by the thesis and includes discussion behind the decisions to undertake the methods. This chapter also outlines the recruitment processes for the research, data collection, and data analysis techniques. Ethical considerations and approvals are also discussed.

Chapter Three presents an integrative synthesis of the research literature. Chapter Three has been peer reviewed and published in PloS One. Permission to reproduce this chapter was not required as the journal is an open access journal and all articles can be reproduced under the Creative Commons Attribution License, if original authors are cited.

Chapter Four presents a content analysis of the treatment and recovery goals of 102 individuals seeking treatment for BPD in a specialist intervention service in New South Wales. Chapter Four has been peer reviewed and published in the Journal of Psychiatric Practice. Permission to reproduce Chapter four is included as Appendix A.

Chapter Five presents a mixed-methods study which includes a quantitative evaluation of the role of an individual's self-identified recovery status and diagnostic status on clinical and personal recovery outcomes. A qualitative thematic analysis of the definitions individuals

ascribe to recovery in BPD is also presented. The manuscript presented as Chapter Five is under review at Social Psychiatry and Psychiatric Epidemiology.

Chapter Six presents an interpretative phenomenological analysis of the responses of 14 individuals with BPD at opposite ends of the recovery continuum to investigate the lived experiences of recovery. Chapter Six has been peer reviewed and published in Borderline Personality Disorder and Emotion Dysregulation. Permission to reproduce Chapter Six was not required as the journal is an open access journal and all articles can be reproduced under the Creative Commons Attribution License, if original authors are cited.

Chapter Seven concludes the thesis and focuses on integrating the findings from the thesis, outlines clinical implications, strengths and limitations of the research, and future research directions.

A preface was included to introduce each chapter which aimed to outline the relationship between chapters, aims of the thesis, and to improve the coherence of the thesis narrative. All papers submitted for peer-review required different referencing styles, however for consistency in the thesis, all references have been formatted using the APA 6th style.

A note on language, the thesis uses the terms; consumer, individual and participant interchangeably. These terms refer to the individuals who have taken part in the research or individuals represented in existing research. Care has been taken to respectfully acknowledge the lived experiences of individuals with BPD.

LIST OF PUBLICATIONS INCLUDED IN THE THESIS

Published Manuscripts

1. **Ng, F.Y.Y**., Bourke, M.E., & Grenyer, B.F.S. (2016). Recovery from borderline personality disorder: A systematic review of the perspectives of consumers, clinicians, family and carers. *Plos One, 11*(8), e0160515. doi: 10.1371/journal.pone.0160515.

2. **Ng, F.Y.Y**., Carter, P.E., Bourke, M.E., & Grenyer, B.F.S. (2019). What do individuals with borderline personality disorder want from treatment? A study of self-generated treatment and recovery goals. *Journal of Psychiatric Practice. 25*(2), 148-155. doi: 10.1097/PRA.0000000000000369

3. **Ng, F.Y.Y.,** Townsend, M.L., Miller, C.E., Jewell, M., & Grenyer, B.F.S. (2019). The lived experience of recovery in borderline personality disorder: A qualitative study. *Borderline Personality Disorder and Emotion Dysregulation. 6*(10), 1-9. doi: 10.1186/s40479-019-0107-2

Manuscripts Under Review

1. **Ng, F.Y.Y.,** Miellet, S., Townsend, M.L., & Grenyer, B.F.S. Clinical and personal recovery in borderline personality disorder: The role of self-identified recovery status and diagnostic status on outcomes. Manuscript under review at Social Psychiatry and Psychiatric Epidemiology.

OTHER PUBLICATIONS ARISING DURING THE CANDIDATURE

Published Manuscripts

1. Rennick-Egglestone, S., Morgan, K., Llewellyn-Beardsley, J., Ramsay, A., McGranahan, A., Gillard, S., Hui, A., **Ng, F.**, Schneider, J., Booth, S., Pinfold, V., Davidson, L., Franklin, D., Bradstreet, S., Arbour, S., & Slade, M. (2019). Mental health recovery narratives and their impact on recipients: Systematic review and narrative synthesis. *Canadian Journal of Psychiatry*. Online First. doi: 10.1177/0706743719846108

2. Grenyer, B.F.S., **Ng, F.Y.Y.**, Townsend, M.L., & Rao, S. (2017). Personality disorder: A mental health priority area. *Australian and New Zealand Journal of Psychiatry, 51*(9), 872-875. doi: 10.1177/0004867417717798.

Published Intervention Manuals

1. **Ng, F.Y.Y**., Marceau, E.M., Leary, S., Jewell, M., Gilbert, S., Stanton, K., Watson, N., Neale, S., Townsend, M.L., & Grenyer, B.F.S. (2018). Peer support for people with personality disorder: A peer and clinician co-facilitated group intervention – Facilitator Manual. Wollongong, Australia. University of Wollongong. ISBN: 978-1-74128-316-7

2. **Ng, F.Y.Y**., Marceau, E.M., Leary, S., Jewell, M., Gilbert, S., Stanton, K., Watson, N., Neale, S., Townsend, M.L., & Grenyer, B.F.S. (2018). Peer support for people with personality disorder: A peer and clinician co-facilitated group intervention – Participant Workbook. Wollongong, Australia. University of Wollongong. ISBN: 978-1-74128-313-6

Manuscripts Under Review

1. **Ng, F.,** Charles, A., Pollock, K., Rennick-Egglestone, S., Cuijpers, P., Gillard, S., van der Krieke, L., Bongaardt, R., Pomberth, S., Repper, J., Roe, J., Llewelyn-Beardsley, J., Yeo, C., Hui, A., Hare Duke, L., Manely, D., & Slade, M. The immediate effect of receiving recorded mental health recovery narratives: Establishing a causal chain model using an experimental design. Manuscript under review at BMC Psychiatry.

2. Roe, J., Brown S., Rennick-Egglestone, S., Repper, J., **Ng, F.,** Yeo, C., Llewelyn-Beardsley, J., Hui, A., Cuijpers, P., Ben-Zeev, D., Thornicroft, G., Manley, D., Pollock, K., & Slade, M. Barriers and enablers to the use of recorded recovery narratives by clinicians. Manuscript under review at the British Journal of Psychiatry.

3. Hui, A., Ramsay, A., Rennick-Egglestone, S., **Ng, F.,** Roe, J., Llewellyn-Beardsley, J., Yeo, C., McGranahan, R., Pollock, K., Thornicroft, G., & Slade, M. Institutional injustice: Implications for system transformation emerging from the mental health recovery narratives of marginalised communities. Manuscript under review at The Lancet Psychiatry.

4. Llewellyn-Beardsley, J., Barbic, S., Rennick-Egglestone, S., **Ng, F.,** Yeo, C., Roe, J., Hui, A., Deakin, E., Hare Duke, L., & Slade, M. Inventory of Characteristics of Recovery Stories (INCRESE): An inventory to characterise recorded mental health recovery narratives. Manuscript under review at Social Psychiatry and Psychiatric Epidemiology.

5. Yeo, C., Hare Duke, L., Rennick-Egglestone, S., Bradstreet, S., Callard, F., Hui, A., Llewellyn-Beardsley, J., Longdon, E., McDonouh, T., McGranahan, R., **Ng, F.,** O'Hagan, M., Pollock, K., Roe, J., & Slade, M. The VOICES typology of curatorial

decisions in narrative collections of lived experiences of mental health service use, recovery or madness: A qualitative study of interviews. Manuscript under review at JMIR Mental Health.

6. Rennick-Egglestone, S., Ramsay, A., McGranahan, R., Llewellyn-Beardsley, J., Hui, A., Pollock, K., Repper, J., Yeo, C., **Ng, F.,** Roe, J., Gillard, S., Thornicroft, G., Booth, S., & Slade, M. The impact of mental health recovery narratives on recipients experiencing mental health problems: Qualitative analysis and change model. Manuscript under review at Plos One.

7. Townsend, M.L., **Ng, F.Y.Y.,** Gray, A.S., & Grenyer, B.F.S. Working with schools and teachers to support students who self-harm: Recommendations from school psychologists. Manuscript under review at Journal of Adolescent Health.

LIST OF PRESENTATIONS ARISING DURING THE CANDIDATURE

Invited Talks

1. **Ng, F.Y.Y.** (2017). *Peer Support Interventions in Borderline Personality Disorder.* Talk presented at the 2nd Carer Peer Work Workshop at Mental Health Carers New South Wales, Sydney, Australia, 7 December, 2017.

2. **Ng, F.Y.Y**., Bourke, M.E., & Grenyer, B.F.S. (2016) *Towards a Conceptual Framework for Recovery in Borderline Personality Disorder.* 6th Annual National Borderline Personality Disorder Conference (Australian BPD Foundation), Sydney, Australia, 6 October 2016.

3. Townsend, M.L., Gray, A.S., **Ng, F.Y.Y**., & Grenyer, B.F.S. (2016) *Self-harm in High School Students: Issues, Controversies and Responses.* 6th Annual National Borderline Personality Disorder Conference (Australian BPD Foundation), Sydney, Australia, 6 October 2016.

Spoken Presentations

1. **Ng, F.,** Roe, J., Rennick-Egglestone, S., & Slade, M. (2019). *How do recovery narratives generate hope and connectedness?* Refocus on Recovery 2019, Nottingham, United Kingdom, 4-6 September 2019.

2. **Ng, F.,** Townsend, M., Jewell, M., & Grenyer, B. (2019). *The stages and processes of recovery in borderline personality disorder: A qualitative study of lived experience.* Refocus on Recovery 2019, Nottingham, United Kingdom, 4-6 September 2019.

3. **Ng, F.,** Townsend, M., Miellet, S., & Grenyer, B. (2019). *The role of self-identified recovery and diagnostic status on outcomes in borderline personality disorder: A mixed-methods study.* Refocus on Recovery 2019, Nottingham, United Kingdom, 4-6 September 2019.

4. **Ng, F.,** Rennick-Egglestone, S., Ramsay, A., Morgan, K., Llewellyn-Beardsley, J., McGranahan, R., Hui, A., Booth, S., & Slade, M. (2019). *How do mental health recovery narratives impact on others?* 13th ENMESH Conference, Lisbon, Portugal, 6-8 June 2019.

5. **Ng, F.,** Rennick-Egglestone, S., Ramsay, A., Morgan, K., Llewellyn-Beardsley, J., McGranahan, R., Hui, A., Booth, S., & Slade, M. (2019). *Mental health recovery narratives: How do they impact people?* Institute of Mental Health Research Day 2019, Nottingham, United Kingdom, 21 May 2019.

6. **Ng, F.Y.Y.,** Marceau, E.M., Townsend, M.L., & Grenyer, B.F.S. (2017). *Peer support for borderline personality disorder: A peer and clinician co-facilitated group intervention.* 11th Annual Conference on the Treatment of Personality Disorders: Understanding Narcissistic Personalities and Other Relationship Complexities, Wollongong, Australia, 2-4 November 2017.

7. **Ng, F.Y.Y.** & Marceau, E.M. (2017). *How to run a peer-led support group for Borderline Personality Disorder.* 11th Treatment of Personality Disorders Conference, Wollongong, Australia, 2-4 November 2017

8. **Ng, F.Y.Y.,** & Grenyer, B.F.S. (2017). *What goals do individuals with Borderline Personality Disorder have for Treatment and Recovery?* New South Wales Borderline Personality Disorder Awareness Week Event, Sydney, Australia, 5 October 2017.

9. **Ng, F.Y.Y.** & Grenyer, B.F.S. (2017). *Qualitative Research: How can the consumer perspective be incorporated in research? Lessons from a study of consumer generated treatment goals.* 15th International Society of the Study of Personality Disorders Congress, Heidelberg, Germany, 25-28 September 2017.

10. **Ng, F.Y.Y.,** Carter, P.E., Bourke, M.E., & Grenyer, B.F.S. (2017). *What goals do individuals with Borderline Personality Disorder have for Treatment and Recovery.* Refocus on Recovery Conference, Nottingham, England, 18-20 September 2017.

11. **Ng, F.Y.Y**. (2016) *Recovery from Borderline Personality Disorder: A Systematic Literature Review and Experiences of Consumers Seeking Treatment.* University of Wollongong, Faculty of Social Sciences HDR Conference, Wollongong, Australia, 11 November 2016.

12. **Ng, F.Y.Y**., Bourke, M.E., & Grenyer, B.F.S. (2016). *Perspectives of Recovery from Borderline Personality Disorder: A Systematic Review.* 4th International Congress on Borderline Personality Disorder and Allied Disorders (ESSPD), Vienna, Austria, 8-10 September 2016.

13. **Ng, F.Y.Y**., Bourke, M.E., & Grenyer, B.F.S. (2016). *Perspectives of Recovery from Borderline Personality Disorder: A Systematic Review.* The Mental Health Service Learning Network (TheMHS) Annual Conference, Auckland, New Zealand, 23-26 August 2016.

14. Bourke, M.E., & **Ng, F.Y.Y**. (2016) *The Project Air Strategy.* ARAFMI Illawarra, Wollongong, Australia, 5 July 2016.

Posters

1. **Ng, F.Y.Y**., Townsend, M.L., Miller, C.E., Jewell, M., & Grenyer, B.F.S. (2019). *The lived experience of recovery in individuals with borderline personality disorder.* 13th ENMESH Conference, Lisbon, Portugal, 6-8 June 2019
2. **Ng, F.Y.Y**., Townsend, M.L., Miller, C.E., Jewell, M., & Grenyer, B.F.S. (2019). *Recovery in borderline personality disorder: A qualitative study of stages and processes.* Institute of Mental Health Research Day 2019, Nottingham, United Kingdom, 21 May 2019.

3. **Ng, F.Y.Y.,** Marceau, E.M., Townsend, M.L., & Grenyer, B.F.S. (2017). *Peer support for borderline personality disorder: A peer and clinician co-facilitated group intervention.* 11th Annual Conference on the Treatment of Personality Disorders: Understanding Narcissistic Personalities and Other Relationship Complexities, Wollongong, Australia, 2-4 November 2017.

4. **Ng, F.Y.Y**, Carter, P.E., Bourke, M.E., & Grenyer, B.F.S. (2016). *What do people with borderline personality disorder want from treatment? A Study of Consumer Generated Recovery Goals.* 10th Annual Conference on the Treatment of Personality Disorders: New Research Frontiers and Discoveries, Wollongong, Australia, 4-5 November 2016.

5. **Ng, F.Y.Y**, Bourke, M.E., & Grenyer, B.F.S. (2015). *Recovery from BPD: A systematic review of the perspectives of consumers, clinicians and carers.* Faculty of Social Sciences (University of Wollongong) HDR Poster Competition, Wollongong, Australia, 14 December 2015.

6. **Ng, F.Y.Y**, Bourke, M.E., & Grenyer, B.F.S. (2015). *Recovery from BPD: A systematic review of the perspectives of consumers, clinicians and carers.* 9th Annual Conference on the Treatment of Personality Disorders: Inside Borderline Personality Disorder, Wollongong, Australia, 6-7 November 2015.

7. McCarthy, K.L., Lewis, K.L., Bourke, M.E., **Ng, F.Y.Y**., & Grenyer, B.F.S. (2015). *Parenting with a personality disorder brief intervention: A pilot study of clinician acceptability.* 9th Annual Conference on the Treatment of Personality Disorders: Inside Borderline Personality Disorder, Wollongong, Australia, 6-7 November 2015.

PRIZES AWARDED DURING THE CANDIDATURE

2019 **Best Poster Presentation (GBP £50)**

Institute of Mental Health Research Day

2018 **Vice Chancellor's Award for Outstanding Achievement in Research Partnership and Impact (AUD $5000)**

Won as part of the Project Air Strategy for Personality Disorders team, University of Wollongong

2016 **Global Challenges PhD Travel Scholarship (AUD $2,000)**

University of Wollongong Global Challenges Scheme

2015 **Best Poster Presentation (AUD $100)**

HDR Poster Competition, Faculty of Social Sciences, University of Wollongong

2015 – 2019 **Australian Government Research Training Program Scholarship (AUD ~ $90,000)**

Australian Government

DECLARATION AND STATEMENT OF AUTHORSHIP

The following publications, completed during the PhD candidature, are reproduced in this thesis. The statements of authorship identify the nature and extent of the intellectual input of the candidate and co-authors for all chapters based on journal articles. The statement of contribution of co-authors is also presented as Appendix B.

The research presented in this thesis was conducted in conjunction with Project Air Strategy for Personality Disorders, based at the University of Wollongong. Project Air Strategy for Personality Disorders had no involvement in the design, interpretation, or funding of the research. As outlined in the University of Wollongong Student Assignment of Intellectual Property (IP) guidelines, the data collected and IP generated as a result of the research conducted is owned by the PhD Candidate (Raper, 2006).

The candidate's primary and secondary supervisors and Head of Postgraduate Studies have signed this declaration to approve the submission of this thesis. All co-authors have signed this declaration as agreement in their contribution to the journal articles.

Chapter Three

> **Ng, F.Y.Y**., Bourke, M.E., & Grenyer, B.F.S. (2016). Recovery from Borderline Personality Disorder: A Systematic Review of the Perspectives of Consumers, Clinicians, Family and Carers. *Plos One, 11*(8), e0160515. doi: 10.1371/journal.pone.0160515.

FYYN designed the study, conducted systematic review searches, curated the data, conducted the formal analysis, and drafted the manuscript. MEB and BFSG contributed to the design of

the study and the interpretation of the data. All authors contributed to the final version of the manuscript.

Chapter Four

> **Ng, F.Y.Y**., Carter, P.E., Bourke, M.E., & Grenyer, B.F.S. (2019). What Do Individuals with Borderline Personality Disorder Want From Treatment? A Study of Self-Generated Treatment and Recovery Goals. *Journal of Psychiatric Practice. 25*(2), 148-155. doi: 10.1097/PRA.0000000000000369

FYYN designed the study, conducted the formal data analysis and interpretation, wrote the first draft of the manuscript. MEB and BFSG contributed to the design and interpretation of the findings. PC was the secondary coder for qualitative data analysis. BFSG provided the archival data. All authors read and approved the final version of the manuscript.

Chapter Five

> **Ng, F.Y.Y.,** Miellet, S., Townsend, M.L., & Grenyer, B.F.S. Clinical and Personal Recovery in Borderline Personality Disorder: The Role of Self-Identified Recovery Status and Diagnostic status on Outcomes. Manuscript under review at Social Psychiatry and Psychiatric Epidemiology.

FYYN designed the study, recruited participants, collected survey data, conducted the statistical data analysis, coded the qualitative data, interpreted the findings, and wrote the first draft of the manuscript. MLT was the secondary coder for the qualitative data analysis and contributed to the interpretation of the results. SM contributed to the statistical analysis and the interpretation of the findings. BFSG contributed to the design of the study and the

interpretation of the results. All authors read and approved the final version of the manuscript.

Chapter Six

> **Ng, F.Y.Y.,** Townsend, M.L., Miller, C.E., Jewell, M., & Grenyer, B.F.S. (2019). The Lived Experience of Recovery in Borderline Personality Disorder: A Qualitative Study. *Borderline Personality Disorder and Emotion Dysregulation. 6*(10), 1-9. doi: 10.1186/s40479-019-0107-2

FYYN designed the study, recruited participants, conducted all participant interviews, conducted the formal data analysis, wrote the first draft of the manuscript. MLT contributed to the interpretation of the results. CM was the secondary coder for qualitative data analysis. MJ contributed to the interpretation of the results. BFSG contributed to the design of the study and interpretation of the results. All authors read and approved the final version of the manuscript.

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LIST OF ABBREVIATIONS

APA	American Psychiatric Association
ARC	Affect Regulation Disorder Clinic
BPD	Borderline Personality Disorder
CAN	Camberwell Assessment of Need
DIB	Diagnostic Interview for Borderlines
DIB-R	Revised Diagnostic Interview for Borderlines
DIPD-IV	Diagnostic Interview for DSM-IV Personality Disorders
DSM-III	Diagnostic and Statistical Manual for Mental Disorders – Third Edition
DSM-IV	Diagnostic and Statistical Manual for Mental Disorders – Fourth Edition
GAF	Global Assessment of Functioning
GAS	Global Assessment Scale
HSRS	Health-Sickness Rating Scale
IP	Internet Protocol
IP	Intellectual Property
IPA	Interpretive Phenomenological Analysis
IQ	Intelligence Quotient
MDD	Major Depressive Disorder
OPD	Other Personality Disorder
PAF	Personality Assessment Form
PD	Personality Disorder
PEO	Person-Environment-Occupation
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSQ	Personality Screening Questionnaire

PTSD	Posttraumatic Stress Disorder
RCT	Randomised Controlled Trial
RDC	Research Diagnostic Criteria
SADS	Schedule for Affective Disorders and Schizophrenia
SAS-SR	Social Adjustment Scale
SCID-I	Structured Clinical Interview for DSM-III-R or DSM-IV Axis I Disorders
SCID-II	Structured Clinical Interview for DSM-IV Axis II Disorders
SCL-90	Symptom Check List-90
SDPD	Schizoid Personality Disorder
SIDP-R	Structured Interview for DSM-III-R Personality
SNAP	Schedule for Non-Adaptive and Adaptive Personality
SPD	Schizotypal Personality Disorder
SPSS	Statistical Package for Social Sciences
UNI	Unipolar Affective Disorder

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER ONE

Introduction

1.1 Preface

The aim of this introductory chapter is to provide an overview of the conceptual background that is used in this thesis. This thesis aims to explore the concept of recovery in individuals with lived experience of Borderline Personality Disorder (BPD), with particular emphasis on personal recovery. This introduction presents the concept of recovery and highlights differences in clinical and personal recovery approaches. The development of personal recovery approaches, current frameworks and criticisms are discussed. The introduction then presents the diagnostic entity of Personality Disorder or more specifically BPD, in accordance to the fifth edition of the Diagnostic Statistical Manual (American Psychiatric Association, 2013). Personal recovery in the context of BPD is then discussed. Linkages between background literature and the aims of the thesis are also presented.

1.2 Recovery

The concept of recovery in mental health is not new, with differing conceptualisations of recovery proposed in the research literature in the past four decades (Davidson & Roe, 2007). Recent empirically-based recovery models have adopted a dimensional approach (Jacobson & Greenley, 2001), where the clearest divide has been associated with clinical and personal notions of recovery (Davidson & Roe, 2007; Slade, 2009).

1.2.1 Clinical and Functional Recovery

Understandings of clinical recovery have derived from the biomedical approaches to classifying health. Dichotomous notions understood through the presence or absence of health, such that The World Health Organisation defines health as:

> *'A state of complete, physical, mental and social well-being and not merely the absence of disease or infirmity'* (World Health Organisation, 1946).

A core premise of clinical recovery is that mental health concerns are biologically based. Despite recognition of psychological and societal influencers, for example through the biopsychosocial model (Engel, 1977), it has been argued that a strong emphasis is still placed on the biological aspects as the causal factor, such that psychological and societal factors are insufficient to trigger illness (Slade, 2009). Recovery in this context focuses on remission and the return to previous levels of functioning, implying the lack of disease or being cured. Therefore expertise is held within mental health professionals, whilst individuals with mental health concerns are viewed to be recipients of treatment.

Longitudinal studies provide important knowledge about illness course, remission and relapse rates, yet these measures provide limited insight into the nuanced changes an individual may

experience as a result of mental health concerns. Additionally, the chronic nature of mental health concerns may indicate that some individuals may achieve some level of symptom remission yet do not return to previous levels of function or experience symptoms yet still lead highly productive lives. Although the importance of measuring functional outcomes and symptom remission is not dismissed, these measurements do not take into consideration the views or lived experiences of consumers nor does it take into consideration the different trajectory of the disorder between individuals[1].

1.2.2 Personal Recovery

The mental health consumer/survivor movement led to an alternative approach to understanding recovery. The movement was initiated by individuals with first-hand lived experience of mental distress or using mental health services. The movement originated in the 1960s, and gained traction following the deinstitutionalisation of mental health services in the 1980s (Beresford, 2010). Using lived experience to advocate for change, the movement was embedded within the civil rights discourse and emphasised that a greater focus on societal and system changes was required, rather than solely the treatment of individuals (Rose, 2018). Hence, the movement advocated for a shift in the manner in which society and systems interacted with individuals with lived experience (Davidson & Roe, 2007). The main assumptions held within biomedical models were challenged and the movement called for a more holistic view of individuals (Slade, 2009, Slade, Oades & Jarden, 2017), such that:

> *'The goal of recovery is not to get mainstreamed. We don't want to be mainstreamed. We say let the mainstream become a wide stream that has room for all of us and leaves no*

[1] Functional recovery is conceptualised as a component of clinical recovery. Studies examining the relationship between clinical and personal recovery have included measures of functioning (such as needs, functioning and quality of life) as subsets of clinical recovery (Macpherson et al., 2016).

one stranded on the fringes. The goal of the recovery process is not to become normal. The goal is to embrace our human vocation of becoming more deeply, more fully human' (Deegan, 2001).

This alternative approach to understanding recovery has emerged within the scientific literature. It is acknowledged that other expressions are used to distinguish between the clinical and personal recovery approaches within the literature including; 'recovery from' vs 'recovery in' (Davidson & Roe, 2007), and 'scientific models' vs 'consumer models' (Bellack, 2006). A commonality within these alternative approaches is that there is not one definition of personal recovery, but rather a reference to the process of living as well as possible, as defined by an individual's own personal definition. The definition adopted by this research is one that is widely accepted and cited, which understands recovery as:

> *'A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness'* (Anthony, 1993, p527)

Personal recovery therefore, refers to the ability to lead meaningful and autonomous lives whilst experiencing symptoms and limitations associated with mental health concerns (Davidson & Roe, 2007; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Conceptual frameworks of personal recovery from serious mental illness based on the lived experiences of consumers have been posited in the literature. Commonalities have appeared across frameworks which have included elements of hope, connection, identity and meaning (Andresen, Oades, & Caputi, 2003; Jacobson & Greenley, 2001; Leamy et al., 2011). For example, a systematic review of empirical studies examining personal recovery in mental

[2]health, synthesised 97 papers to develop the CHIME framework (Connection, Hope, Identity, Meaning and Empowerment) (Leamy et al., 2011). Whilst questions over the compatibility of clinical and personal recovery approaches have emerged, empirical evaluation through correlational studies has identified that these are related yet distinct constructs (Macpherson et al., 2016; Resnick, Rosenheck, & Lehman, 2004; Roe, Mashiach-Eizenberg, & Lysaker, 2011; Tse, Davidson, Chung, Ng, & Yu, 2014).

The personal recovery model also faces some criticisms. The individualistic stance towards mental health has been criticised within the literature, where greater consideration of the social and interpersonal aspects is required (Price-Robertson, Obradovic, & Morgan, 2016; Tew et al., 2011; Topor, Borg, Di Girolamo, & Davidson, 2011). This is particularly notable in the cross-cultural applicability of personal recovery in non-Anglophone countries, such as collectivist societies, where greater value is placed on family or community, compared to individual goals and pursuits (Tse & Ng, 2014). Relationally-based models of recovery stipulate that recovery does not occur in isolation, instead social relationships play a role in promoting a sense of inclusion, connectedness, and provides opportunity for the development of identity beyond that of a patient (Price-Robertson et al., 2016). Additionally, recovery has been argued to fulfil a neoliberal agenda in order to cut services and supports required by individuals with mental health concerns (Rowe & Davidson, 2016). These arguments have lent to a greater emphasis on citizenship and human rights. Citizenship emphases the role the wider society has in promoting recovery in individuals with mental health concerns (Hamer, Rowe & Seymour, 2018). An example of a citizenship and rights promoting intervention is the World Health Organisation's Quality Rights project which aims to reforming and

[2] Whilst the use of recent references is important, one goal of the introduction is to provide a historical overview of the recovery field. Therefore, the use of older references was necessary.

improving access to mental health services through the promotion of human rights in high, middle and low income countries (World Health Organisation, 2019).

Despite these criticisms, personal recovery frameworks have been translated into policy, with the majority of developed countries adopting frameworks for recovery-oriented mental health services. For example, in Australia the National Framework for Recovery-Oriented Mental Health Services (Commonwealth of Australia, 2013) was introduced in 2013. This framework provided evidence-based guidance for health professionals and services in improving mental health service delivery.

1.3 Personality Disorder

Personality disorder is a recognised mental illness classified using the by the Diagnostic Statistics Manual (DSM; American Psychiatric Association [APA], 2013) and the International Classification of Disease (World Health Organisation, 1993). Globally, it is estimated that approximately 7.8% of the population experiences a personality disorder (Winsper et al., 2019). Similarly, prevalence of personality disorder is estimated at 6.5% of the Australian population (Jackson & Burgess, 2000).

Personality disorder describes an enduring pattern of inner experience that is considered pervasive and inflexible (APA, 2013). Behaviour in personality disorder deviates from social and cultural norms. The DSM-5 describes 12 personality disorders across three clusters, based on phenomenological observations. Cluster A describes personality disorders with odd or eccentric traits, including paranoid, schizoid and schizotypal personality disorders. Cluster B describes individuals who may present with dramatic, emotional or erratic traits, these include borderline, anti-social, histrionic, and narcissistic personality disorders. Cluster C

describes personality disorders which may manifest through anxious or fearful traits, for example avoidant, dependent and obsessive-compulsive personality disorders.

1.3.1 Borderline Personality Disorder

Borderline Personality Disorder (BPD) is a severe mental health problem, characterised by difficulties with emotion regulation, interpersonal difficulties, identity and impulsivity (APA, 2013). BPD is estimated to affect 1-5.9% of the global population (APA, 2013; Jackson & Burgess, 2000). The large discrepancy in prevalence estimation may be associated with differences in diagnostic systems used worldwide, however may be more reflective of the limited data available on the diagnostic rates of personality disorder. For example in Australia, population data on personality disorder is limited and often not reported as a separate diagnostic entity but rather included in an 'other' category (Grenyer, Ng, Townsend & Rao, 2017).

The prevalence of BPD in inpatient settings is significantly higher compared to community settings, where approximately 20% of all mental health inpatients are represented by BPD (Gunderson et al., 2011). Within community samples, the prevalence of BPD has been identified to affect females and males at a similar rate (Tomko, Trull, Wood & Sher, 2014).

A systematic review of 33 randomised-controlled trials evaluating the effectiveness of psychotherapeutic interventions for BPD (for example Dialectical Behavioural Therapy, Schema Therapy, Transference Focused Psychotherapy, and Mentalisation-Based Treatment), indicated that treatment led to improved outcomes, however no one treatment was superior to another (Cristea et al., 2017). Despite high service utilisation and high costs associated with the treatment, a recent systematic review identified the cost saving capacity for health

services when treating individuals with evidence-based psychotherapy (Meuldijk, McCarthy, Bourke & Grenyer, 2017).

High rates of co-morbidity with other personality disorders and mental health concerns have also been observed (Zimmerman & Mattia, 1999), particularly with Axis I and Axix II disorders (Lenzenweger, Lane, Loranger & Kessler, 2007). Comorbidity with other disorders have contriuted to the controversial nature of BPD, yet the research literature has argued that BPD is a distinct diagnosis. Arguments to support BPD as a distinct diagnositc entity have included the identification of both internalising and externalising features of BPD (Eaton et al., 2011), and the identification of differing trajectory of the disorder, rates of remission and functioning between BPD and other disorders (including schizophrenia, major depression, and other personality disorders) (Ng, Bourke & Grenyer, 2016). Additional arguments for the changes to the conceptualisation of BPD have emerged through the argument over the phenomenological similarities between complex post-traumatic stress disorder and BPD (Lewis & Grenyer, 2009). Confusion between correlation and causation, and the identification through epidemiological studies that not all individuals with a history of childhood trauma develop symptoms of BPD (Fossati, Madeddu & Maffei, 1999) have contradicted these arguments.

A core tenant of this thesis is that BPD is a distinct diagnostic entity. It is acknowledged that the personality disorder field is in transition to a dimensional model, focused on personality traits, severity, functional impairment (Bach & First, 2018). The current research adopts the categorical definition of BPD as conceptualised in the Diagnostic Statistics Manual Fifth Edition (APA, 2013). There are nine diagnostic criteria for BPD, with individuals indicating five or more items meeting criteria for BPD. Criteria include;

1. Frantic efforts to avoid real or imagined abandonment

2. A pattern of unstable and intense interpersonal relationships characterised by alternating between extremes of idealisation and devaluation

3. Identity disturbance: markedly and persistently unstable self-image or sense of self

4. Impulsivity in at least two areas that are potentially self-damaging (eg spending, sex, substance abuse, reckless driving, binge eating)

5. Recurrent suicidal behaviour, gestures, or threats or self-mutilating behaviour.

6. Affective instability due to a marked reactivity of mood (eg intense episodic dysphoria, irritability or anxiety usually lasting a few hours and only rarely more than a few days)

7. Chronic feelings or emptiness

8. Inappropriate, intense anger or difficulty controlling anger (eg frequent displays of temper, constant anger, recurrent physical fights)

9. Transient, stress-related paranoid ideation or severe dissociative symptoms

1.4 Personal Recovery and BPD

Personal recovery frameworks have predominately been developed with a focus on individuals with severe mental illness such as psychosis, due to its severity (Andresen et al., 2003). Yet, research examining the clinical and functional outcomes of schizophrenia and BPD have identified differences in trajectory of the disorders, exemplifying the disorders as separate entities (Gunderson et al., 2011; McGlashan, 1985, 1986). Differences in clinical

characterisations between disorders indicate that further exploration in the applicability of current personal recovery frameworks for all mental illnesses is required.

Currently no conceptual framework describing personal recovery BPD has been proposed in the literature. To date, the lived experience of individuals with personality disorder has attracted some attention in the literature, where research has discussed the impact of the BPD diagnosis (Horn, Johnstone, & Brooke, 2007; Lariviere et al., 2015; Nehls, 1999), the stigmatised nature of the disorder (Bonnington & Rose, 2014; Horn et al., 2007; Nehls, 1999; Straker & Waks, 1997), experiences with treatment (Holm, Berg, & Severinsson, 2009; Katsakou et al., 2012; Nehls, 1999, 2001; Perseius, 2003; Rogers & Acton, 2012; Tan et al., 2018) and consumer experiences of the disorder (Briand-Malenfant, 2012; Lariviere et al., 2015; Miller, 1994). However, specific experiences of recovery in BPD have been minimally explored. Therefore, the first aim of the thesis is to; *systematically review and consolidate current empirical longitudinal and qualitative research associated with the perspectives of consumers, clinicians, family and carers on recovery in BPD,* allowing for the identification of gaps in the literature to guide the direction of the thesis.

One paper highlighted that some individuals have goals to improve their capacity for emotion regulation and relationships, reducing suicidality, accepting self, and practical achievements (Katsakou et al., 2012). Goals were often identified to conflict with the service or treatment targets of evidence-based interventions, such that the focus on specific behavioural targets may not mirror an individual's treatment and recovery goals (Katsakou et al., 2012). Therefore, to confirm prior research there is a need to describe the treatment and recovery goals of individuals who are actively seeking treatment for BPD. This gave rise to the second aim of the thesis; *to describe the content of personally meaningful treatment goals of individuals who are seeking treatment for BPD.*

Studies examining recovery through the perspectives of individuals with lived experience of BPD have identified that individuals question the conceptualisation of recovery, as it implies a curative stance (Holm & Severinsson, 2011; Katsakou et al., 2012; Lariviere et al., 2015). Alternative concpetualisations proposed have included 'progress', 'learning', or 'journey', as these are considered to be more representative of an individual's experience. Yet, it is unclear as to how individuals personally define recovery in BPD. This resulted in the third aim of the thesis; *to describe how individuals define and conceptualise recovery in BPD.*

Understanding the manner in which individuals define recovery is important because the personal recovery model places emphasis on the perspectives of individuals with lived experience. Individuals are considered experts by experience, and can assist to understand how recovery may be facilitated (Davidson & Roe, 2007). Therefore, it is plausible that there may not be concordance between an individual's diagnostic status and their personal definition of recovery in BPD, and an individual's personal definition of recovery could have an effect on outcomes. Although it is known that clinical and personal recovery are considered related yet distinct constructs in serious mental illness (Resnick, Rosenheck, & Lehman., 2004; Roe, Mashiach-Eizenberg, & Lysaker., 2011; Tse, Davidson, Chung, Ng, & Yu., 2014), no quantitative study exploring the association between clinical and personal recovery outcomes have been conducted in the context of BPD. This gap in the literature gave rise to the fourth aim of the thesis; *to empirically evaluate the role of one's self-identified recovery status and diagnostic status on clinical and personal recovery outcomes.*

Qualitative studies with individuals seeking treatment for personality disorder broadly, have described recovery as a process of reconciliation of self and other, through the development of relationships, and integration into the community (Gillard, 2015; Shepherd, Sanders, & Shaw, 2017). Within the context of evidence-based treatment, recovery processes were

identified to be a balance between ‘fighting ambivalence and committing to taking action’, ‘moving from shame to self-acceptance and compassion’ and ‘moving from distrust and defensiveness to opening up to others’ (Katsakou, Pistrang, Barnicot, White & Priebe, 2017, p3-4). Managing therapeutic challenges such as self-exploration, therapy structure, interpersonal difficulties and balancing support and independence, have also been identified as important processes for recovery in services (Katsakou et al., 2017). Although understanding recovery within the context of treatment is important, given the reported difficulties in access and the desire for services (Grenyer, Ng, Townsend & Rao, 2017), this may not provide understanding of the experiences of individuals who may or may not be accessing services.

The stages of recovery have minimally been discussed, with general stages of recovery, such as ‘no progress’ ‘recovery fluctuating’ ‘able to deal with things in a better way but not (fully) recovered’ and ‘recovered’ proposed within the literature (Katsakou et al., 2016). These stages provide an understanding of the differences between individuals at different stages of recovery. The understanding of stages in BPD may be further supported by recommendations for the examination of recovery at opposite ends of the spectrum (Spaniol, 2002). The gaps in the literature surrounding the processes and stages of recovery in BPD resulted in the fifth and final aim of the study; *describe the stages and processes associated with recovery in BPD, through the perspectives of individuals at opposite ends of the recovery continuum.*

1.5 Summary of the Aims of the Thesis and Research

The overarching aim of the thesis was to empirically explore and describe the experience of recovery in BPD through the perspectives of individuals who have lived experience. Based on the above background literature, the aims of this thesis by compilation was five-fold and summarised below:

1. Systematically review and consolidate current empirical longitudinal and qualitative research associated with the perspectives of consumers, clinicians, family and carers on recovery in BPD (see Chapter Three).
2. Describe the content of personally meaningful treatment goals of individuals who are seeking treatment for BPD (see Chapter Four).
3. Describe how individuals define and conceptualise recovery in BPD (see Chapter Five).
4. Empirically evaluate the role of one's self-identified recovery status and diagnostic status on clinical and personal recovery outcomes (see Chapter Five).
5. Describe the stages and processes associated with recovery in BPD, through the perspectives of individuals at opposite ends of the recovery continuum (see Chapter Six).

CHAPTER TWO

METHODS

2.1 Preface

The aim of this chapter is to describe and justify the methods adopted by the research. A mixed-methods approach was utilised to describe and explore the concept of recovery in BPD through the perspectives of individuals with lived experience. This chapter begins with an overview of the thesis and the mixed-methodology approach, then discusses the different phases of data collection, data analysis techniques, and ethical considerations for the research.

Each chapter in this thesis by compilation includes a detailed methods section which outlines the approach undertaken specifically within each study. The purpose of this chapter is to provide additional justification for the chosen methods. Linkage between the methods used and corresponding research aims have been made to provide context for the discussion.

2.2 Study Design

The research employed the use of a mixed-methods approach to investigating the aims of the research. Mixed-methods approaches to research emphasise the mixing of research methods to provide multiple pathways to understanding a research question (Creswell & Plano Clark, 2018). This approach to the thesis was chosen given the nature of questions within clinical and health services research. Quantitative methods allow the researcher to collect inferential and empirical data allowing for the statistical analysis and objective insight into the phenomena. Qualitative research however, allowed for the in-depth exploration of lived experience of participants to explain the phenomena (Creswell & Plano Clark, 2018). Mixed-methods can assist with the corroboration of findings, where the qualitative findings can be used to further understand and support the interpretation of quantitative findings and support methodological triangulation (Creswell & Plano Clark, 2018).

Further reasoning to include qualitative components in the research pertains to the concept of personal recovery. The concept asserts that an individual's lived experience is central, as such qualitative methods can assist to illuminate the perspectives of individuals who may not normally be represented. The recovery perspectives of individuals with lived experience of BPD have been minimally explored within the research literature.

2.3 Phases of Research

The research occurred across four phases and were sequentially conducted. Whilst these research phases were sequential, that is conducted one after another, an iterative approach was undertaken with the goal of each study informing the next. Table 1 outlines the research phases, and the corresponding research aim and thesis chapter.

Ethics clearance to conduct research from a university human research ethics committee is an essential component which demonstrates that researchers have considered what is required as part of the research and the potential harms the research may have on participants. The research was conducted in line with the World Medical Association's Declaration of Helsinki which outlines the ethical principles that should be adhered to when conducting medical research involving people (World Medical Association, 2013). Whilst the research conducted did not include the evaluation of an intervention, the research conducted did involve the discussion of an individual's recovery in BPD which can be considered sensitive and potentially traumatic.

The following section of the methods chapter outlines methods of data collection, data analysis techniques, and the ethical considerations at each research phase.

Table 1 Overview of linkage between data collection technique and corresponding research aims

Phase	Corresponding Research Aim	Data	Analysis Approach	Corresponding Chapter in the Thesis
1: Systematic Review	Systematically review and consolidate current empirical longitudinal and qualitative research associated with the perspectives of consumers, clinicians, family and carers on recovery in BPD. The identified limitations and gaps in the literature will inform the aims of the thesis	Published peer-reviewed papers	Thematic synthesis	Chapter Three
2: Treatment Goals	Describe the content of personally meaningful treatment goals of individuals who are seeking treatment for BPD	Archival clinical data	Qualitative content analysis	Chapter Four
3: Self-identified recovery and diagnostic status on outcomes	1. Identify how individuals define and conceptualise recovery in BPD 2. Empirically evaluate the role of one's self-identified recovery status and diagnostic status on clinical and personal recovery outcomes	Survey data using standardised questionnaires	Inferential and multivariate quantitative analysis	Chapter Five
4: Lived experience of recovery	Describe the stages and processes associated with recovery in BPD, through the perspectives of individuals at opposite ends of the recovery continuum	Semi-structured qualitative interviews	Qualitative interpretative phenomenological analysis	Chapter Six

2.4 Phase One: Systematic Review

A systematic review is a technique which consolidates evidence about a research question, through the application of pre-defined eligibility criteria and explicit methodology to reduce bias (Higgins & Green, 2011). A synthesis of existing literature allows for the identification of gaps in the literature and the development of a programme of work that provides an original contribution, rather than the duplication of existing knowledge. Therefore, the first phase of the research (Chapter Three) aimed to synthesise the literature by answering the research question: *How do consumers, clinicians, family and carers understand and experience recovery from Borderline Personality Disorder?*

Given the contrasting definitions of recovery, this review sought to understand the literature from both perspectives, that is clinical and personal recovery, to gain a holistic overview. The perspectives of consumers, clinicians, family and carers were included, as recovery is known to not occur in isolation (Price-Robertson, Obradovic & Morgan, 2016).

The systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) which outline a 27 item checklist and flow diagram for the reporting of systematic reviews. To promote transparency, the review protocol which outlined the databases searched, inclusion and exclusion criteria, and types of studies included, was registered on PROSPERO prior to the data extraction (Appendix C). A detailed search strategy was included as part of the protocol registration on PROSPERO (Appendix D). The registration of the protocol enabled researchers to identify and avoid producing duplicate systematic reviews (Wager & Wiffen, 2011).

An assessment of included studies is conducted within systematic reviews to appraise the methodological quality of studies. The studies included in this systematic review adopted two

methodological designs – longitudinal and qualitative studies. Given the differences in these methods, longitudinal and qualitative studies were assessed separately using criteria adopted from published systematic reviews. The quality of longitudinal studies was assessed using a criteria adapted from Kuijpers and colleagues (2004) and Luppino and colleagues (2010). Domains assessed included the study population, follow-up duration, baseline responses, follow-up responses, and measures used. The quality of qualitative studies was assessed using criteria adapted from Kuper and colleagues (2008) and Daly and colleagues (2007). Domains assessed included clarity, appropriateness of methods, data collection, data analysis, transferability of findings, ethical considerations, and on Daly and colleagues' (2007) hierarchy of qualitative evidence.

Systematic reviews are exempt from ethics approval processes, as they do not involve human participants. Ethics approval was, therefore not sought for this phase of the research.

2.5 Phase Two: Treatment Goals

Phase Two (Chapter Four) focused on understanding the treatment goals of individuals who were entering a specialist intervention service for people with a diagnosis of BPD. Treatment goals were chosen as the focus of this phase, due to disparities identified between treatment goals and the recovery goals of individuals as noted within the literature. Phase Two of the thesis will assist to clarify the literature and provide understanding into what individuals may want from treatment. Findings will have important implications for the delivery of person-centered services for people with BPD.

Phase Two used archival data collected as part of the longitudinal evaluation of individuals seeking treatment at the Affect Regulation Disorder Clinic (ARC), a health service and university partnership focused on the treatment of personality disorder within the community.

Data for the evaluation of the ARC was collected longitudinally at each treatment session. An individual's goals for treatment were collected during the intake assessment and at discharge from the service. Data used in this phase pertained only to goals collected in response to the Targets Complaints Measure (Battle et al., 1966) by individuals during the intake assessment. This was chosen as the study aimed to understand the types of goals individuals may have, rather than change in goals over time as a result of therapeutic intervention.

Archival data from a clinical intervention service was chosen for this phase of the research as the systematic review indicated that there were differences between the targets of mental health services and goals of individuals with lived experience (Chapter Three, Ng, Bourke, & Grenyer, 2016). Analysis of goals arising from a clinical setting may assist to illuminate differences between individual's goals and the treatment targets of services.

Qualitative content analysis using an inductive conventional approach was chosen as the method of analysis. This approach provides flexibility, where the aim is to describe and classify a phenomenon when there is a limited theoretical basis (Hsieh & Shannon, 2005). This was pertinent for this phase, as the study utilised data which was already collected as part of a wider study and allowed for a systematic approach to understanding a significant proportion of data.

Ethics approval had previously been sought during active data collection periods from the University of Wollongong Social Sciences Human Research Ethics Committee and Illawarra Shoalhaven Local Health District.

2.6 Phases Three and Four

Phases Three and Four were two separate studies conducted sequentially, with ethics approval received for both phases in the same application. Project Air Strategy's Consumer

Advisory Committee was engaged to provide feedback during the design stage of the study. The role of the consumer advisory committee was to provide feedback and advice on the design of the study. This advisory committee consisted of five individuals with lived experience of BPD. The language and the manner in which questions were phrased were commented upon by the advisory committee.

Ethics approval from the University of Wollongong Social Sciences Human Research Ethics Committee was received prior to the start of data collection in Phases Three and Four. Initial ethics approval was received in July 2017. An amendment to change the methods for data collection was sought in November 2017. Changes requested pertained to the inclusion criteria and shift to online methods of data collection (Phase Three). Ethics approval for this amendment was received in December 2017 (University of Wollongong Social Sciences Human Research Ethics Committee HE16/215) (See Appendix E).

The participant information sheet and consent form (Appendix F) was presented as the landing page of the online survey, where individuals had to provide consent for participation in order to proceed with the survey. Consent for participation provided at the time of starting the online survey was inclusive of Phases Three and Four. Additional verbal consent was requested from participants in Phases Four at the start of the semi-structured interview.

To ensure the wellbeing of participants, advice on the presentation of the survey was sought from three non-government organisations in Australia. A number of safeguards were embedded with the online survey (Phase Three) based on the recommendations. Firstly, an exit option was provided on each page of the survey, which led participants to a page of contact details of support services, prior to exiting the survey. Secondly, the contact details of support services were presented again at the end of the survey. In Phase Four, the researcher monitored the interview and offered to stop the interview if distress occurred.

Rigor in the qualitative research refers to the trustworthiness of the research process (Maher, Hadfield, Hutchings & de Eyto, 2018) and may be operationalised through four constructs, credibility, transferability, dependability and confirmability (Cypress, 2017). Rigor was ensured in the qualitative components of Phases Three and Four through a number of mechanisms. First, credibility refers to the accurate depiction of an individual's lived experience. In this Phase, the consumer advisory committee was consulted at regular intervals design stages of the study. Additionally, one member of the consumer advisory committee provided feedback on the analysis, where their feedback was integrated to strengthen the paper. Triangulation of interpretations occurred through the cross-checking of interpretations with the researcher's reflexive journal and the second coder. Second, transferability refers to the generalisability of the data and was enhanced through using a purposive sampling method of individuals who are representative of the population group, and through the use of an interview schedule (Appendix H) which allowed for understanding of an individual's experience of recovery. In Phase Three, data collection continued for a fixed period of six weeks, whilst in Phase Four, data collection continued till all participants who were interested in taking part had been interviewed. Third, dependability was ensured through having two independent coders with expertise in psychology and health services research to categorise and summarise the data into themes. Double coding occurred for 20% of the transcripts in Phase Three and 10% of the data in Phase Four. Differences in the proportion of transcripts was due to the differences in sample size for each phase. The development of themes was an iterative process, whereby discussion of the coding aided their generation. Fourth, confirmability in Phases Three and Four was ensured through the PhD candidate keeping a reflexive journal which documented the researcher's thoughts about preliminary themes and the research process. The reflexive journal also allowed the researcher to reflect upon

assumptions they may have about the data and was considered an additional source for data triangulation.

2.6.1 Phase Three: Self-Identified Recovery Status, Diagnostic Status and Outcomes

Phase Three (Chapter Five) consisted of a cross-sectional study examining an individual's self-identified recovery status and diagnostic status on clinical and personal recovery outcomes. Cross-sectional studies are observational studies which use questionnaires and surveys to collect and analyse data from a representative sample at one time point (Mann, 2003). The current literature describes clinical and personal recovery as complementary with correlational studies reporting these constructs as distinct yet related (Resnick, Rosenheck, & Lehman, 2004). It is unknown how this applied to BPD and whether an individual's perception influences clinical and/or personal outcomes.

In this phase, individuals were invited to take part in an online survey (Appendix G). This method of data collection was chosen as it allowed for wider reach, leading to a greater sample size and convenience as potential participants could access the survey at any time (Kraut et al., 2004). This greatly benefits the design of the study as it maximises the reach; not restricting the study to people who were geographically close to the researcher (thereby limiting generalisability). The online survey platform used in this research was Survey Monkey, as it was freely accessible via Project Air Strategy. The anonymous nature of online research could allow individuals to participate more freely and provide more accurate responses compared to face-to-face research designs (Duffy, Smith, Terhanian, & Bremer, 2005). This was particularly pertinent in research with individuals with lived experience of BPD given the stigmatised nature of the disorder (Aviram, Brodsky, & Stanley, 2005; Lam,

Poplavskaya, Salkovskis, & Hogg, 2016). Demographic questions were included in the online survey to gain an overview of the sample.

Diagnostic status was operationalised using the McLean Screening Instrument (MSI-BPD) (Zanarini et al., 2003), a commonly used screening measure in research studies to detect the presence of BPD (Miller, Lewis, Huxley, Townsend, & Grenyer, 2018). Self-identified recovery status was determined by asking individual's to provide their personal definition of recovery and whether they identified with being recovered in accordance to their own definition. This method of determining recovery status was favoured as it provided a subjective rating of recovery, aligning with the personal recovery model which stipulates that individuals are experts of their own lived experience (Anthony, 1993).

Clinical recovery was operationalised using the Mental Health Inventory-5 (MHI-5; Berwick et al., 1991) and the World Health Organisation Disability Assessment Scale (WHODAS 2.0; Ustun, 2010). These measures were chosen as they have previously been widely used in research into personality disorders in assessing general psychopathology (Karukivi, Vahlberg, Horjamo, Nevalainen, & Korkeila, 2017) and functioning (Keely, Flanagan, & McCluskey, 2014; Miller et al., 2018). Personal recovery was measured using the Recovery Assessment Scale Domains and Stages (RAS-DS; Hancock, Scanlan, Bundy, & Honey, 2016) and the World Health Organisation Quality of Life-BREF scale (WHOQOL-BREF; The WHOQOL Group, 1998).

Bivariate and multivariate data analysis was conducted in IBM Statistical Package for Social Sciences version 24 (SPSS) and was cleaned prior to analysis. One disadvantage to online research is the risk of multiple submissions made by one individual. To avoid this, the internet protocol (IP) address of responders submitted were monitored for duplication using Microsoft Excel. Duplicate submissions from the same IP address were cross compared for

date, time and consistency of responses. In instances where the survey was restarted in a short amount of time (for example minutes), the second attempt at the survey was included for analysis. When there was a more substantive time difference (for example weeks), the first submission of survey was included for the analysis. Data was screened and only included in the final analysis if compulsory sections of the questionnaire were completed. Compulsory sections included questions surrounding self-identified recovery status and the completion of the MSI-BPD.

2.6.2 Phase Four: Lived Experience of Recovery

Phase Four consisted of a qualitative semi-structured interview about the recovery experiences of individuals with BPD. Participants in Phase Four drew from the Phase Three sample, where individuals were invited to leave their contact details at the end of the online survey for follow-up. Semi-structured interviews were guided by a topic guide (Appendix H) which consisted of broad questions of interest and prompts, yet provided flexibility for the researcher to further enquire about or clarify responses provided by the participant. As recovery is considered a personal journey which varies between individuals, this precluded the use of standardised interview schedule which specifies the wording and order of questions. Participants had the choice of participating in face-to-face, telephone (participants based in Australia) or skype (internationally based participants) interviews. Face-to-face interviews were held on campus at the University of Wollongong, Wollongong campus. Interviews were scheduled to take one hour.

Interpretative phenomenological analysis (IPA) was used as the overarching methodology to understand participants' experiences and the ascribed meaning associated with the recovery journey in BPD (Smith & Osborn, 2009). IPA was the chosen methodology due to its idiographic nature, which allows for an account of lived experience to be interpreted through

the perspectives of individuals, rather than from a pre-existing theoretical framework (Smith & Osborn, 2015). Additionally, IPA is an appropriate analysis tool to use to gain in-depth knowledge in areas where there is limited evidence. Personal recovery in the context of BPD has attracted limited research investigation, therefore using IPA allows for a detailed and robust method of capture the perspectives of individuals with lived experience. This is particularly compatible with the core tenants of the personal recovery model, which recommends the promotion of recovery through an individual's personal definitions and goals.

Small samples sizes are employed in IPA, where participants are recruited to provide an in-depth account of the phenomenon of interest through their own perspectives (Peat, Rodriguez & Smith, 2018). In IPA, the researcher plays an important and active role in the interview and data analysis process. Whilst it is assumed that individuals are experts of their own lived experience, the researcher's role during the interview is to guide and elicit in-depth responses (Peat et al., 2018). Interpretation of narrative is achieved through an iterative process involving the movement between smaller and larger units of meaning (Peat et al., 2018). During the interpretation phase, the researcher acknowledges their prior knowledge and assumptions about the data. Reflexivity in this phase of research was promoted through the reflection of the interactions between the participant and the researcher, and captured through field notes at the end of each interview. The analysis of data was supported through the use of NVivo 11. All participant responses were transcribed verbatim and anonymised prior to analysis.

2.6.3 Inclusion and Exclusion Criteria

To acknowledge the differing perspectives of recovery individuals may have, the inclusion criteria was broad to include all individuals who had previously received a diagnosis of BPD

from a health professional. Individuals did not have to be in treatment at the time of participation and individuals with recurrent suicidal behaviour, gestures, threats, or self-mutilating behaviour were not excluded from the study, so long as they met the inclusion criteria. Individuals were excluded from the study if, they were;

1. Under the age of 18
2. Could not provide informed consent, and
3. Could not complete the online survey in English

2.6.4 Recruitment of Participants

All participants were self-selected by responding to invitations to participate in the research. Participants were recruited at arm's length via email, letter or through websites. Potential participants were made aware of the study through five methods:

1. Open email invitations sent to relevant community groups (e.g. Association for Relatives and Friends of the Mentally Ill),
2. Websites to advertise the study (e.g. Australian Psychological Society, NSW Mental Health Commission, Project Air Strategy for Personality Disorders),
3. Email updates to individuals who had voluntarily signed up to receive email updates from Project Air Strategy for Personality Disorders, based at the University of Wollongong,
4. Social media updates to individuals who had voluntarily followed organisations who consented to assist with the recruitment of participants, and
5. Snowball recruitment process was used, such that participants were asked to pass on the study information to others they know who fit the inclusion criteria and might be interested.

Participants were invited to leave their email address at the end of the online survey (Phase Three) for future contact. Individuals were contacted twice via email with an invitation to take part in the semi-structured interview as part of Phase Four. Interviews were scheduled with individuals who expressed interest to take part.

2.7 Significance of the Research

This thesis contributes to the evidence base of knowledge surrounding the recovery of individuals with BPD. The findings from the research will inform clinical practice and propose future research directions to improve treatment and services for individuals with BPD. The increasing requirement for mental health services to be recovery-oriented, and the high costs associated with treatment, reinforces the need to identify the needs and recovery conceptualisations of individuals, in order to incorporate their perspectives into the delivery of treatment and services. Health professionals may benefit from this research as the findings may provide understanding of the elements of recovery through the perspectives of individuals with lived experience, that are not currently captured by theoretical models of change in BPD. The findings will also provide awareness of the factors which promote recovery, and effect of individual perspectives on outcomes. Individuals with lived experience of BPD may also benefit from the findings of the research in the long term through more recovery-focused services and treatments. Short term benefits may also be experienced through the sharing and receiving of narratives. Researchers may benefit through the identification of future directions for the development of new interventions.

Overall, gaining an understanding of what recovery means through the perspectives of individuals with lived experience of BPD may translate to treatments which are more personalised, which may result in improved services and outcomes.

2.8 Limitations and Delimitations of the Research

Whilst care was taken to design the research in a manner which would answer the research aims and be representative of the lived experiences of individuals with BPD, it is acknowledged that a number of delimitations were defined by the researcher and the research design is not without its limitations.

First, the research specifically focused on the experiences of individuals with BPD, rather than personality disorder generally. This is due to the clinical differences between different personality disorders (Gunderson et al., 2010; McGlashan et al., 1986). Additionally, individuals with BPD account for the high proportion of individuals seen within mental health services (Beckwith, Moran & Reilly, 2014).

Second, despite the ability to diagnose BPD in individuals under the age of 18 (National Health Medical Research Council, 2012), the research focuses on the experiences of individuals above the age of 18. Third, whilst it is acknowledged that recovery is a multi-faceted term, the research was specifically focused on the perspectives of individuals with lived experience. Studies of carers of individuals with personality disorder indicate high levels of psychological distress and burden (Bailey & Grenyer, 2014). The views of carers may be influenced their own experiences and may differ to those of individuals with lived experience.

Fourth, the research relied on cross sectional data which only examined the experiences of individuals at one point in time. To understand the concept of recovery using a cross-sectional data may be limited, as this may not capture the fluctuations, processes and changes an individual experiences. The responses collected as part of cross-sectional research may be influenced by an individual's current affective state, which may differ to their usual

experience. Although cross-sectional data can assist to illuminate the relationships between variables, it is unable to provide an indication of cause and effect (Mann, 2003). Therefore, findings from quantitative data needs to be interpreted with care. In an attempt to minimise this limitation, a qualitative study conducted in Phase Four included individuals at the opposite ends of the recovery journey, to allow for comparison between individuals at different stages to gain a more nuanced view. A longitudinal design may have provided a more comprehensive view, however the resource and time constraints precluded its use.

Fifth, the research used a mixture of clinical and self-report diagnostic data. Individuals recruited to participate in Phases Three and Four had received a diagnosis of BPD, provided by a health profession. The diagnostic status of individuals, in the research study, was determined using the McLean screening instrument, which provides an indication for the presence of BPD (Zanarini et al, 2003). Structured clinical interviews were not be used to confirm an individual's diagnosis, therefore the generalisability of the findings may be limited to individuals who may experience traits associated with BPD. Resources and time constraints limited the ability of the researcher to engage in this process.

Sixth, one advantage to the online survey is the ability to disseminate to a large sample of individuals. Online research may lead to a wider range of responses, but may favour individuals who are computer literate and have access to the technology. Therefore the findings from the current research may not capture the experiences of individuals who do not have these means or capacity. Additionally, the recruitment of individuals via social media and mental health organisations may favour individuals who are actively seeking support for BPD. This may not capture the views of individuals who are no longer in need of services, don't find services helpful or are recovering outside the mental health system. This may be overcome with the inclusion of snowball sampling as a method of recruitment.

Last, the research used self-report data. Whilst self-report data has advantages, for example in the ease of implementation in large samples, there are limitations associated with self-report data. Response bias and social desirability may be a limitation associated with the collected data.

CHAPTER THREE

Phase One

Recovery from Borderline Personality Disorder: A Systematic Review of the Perspectives of Consumers, Clinicians, Family and Carers

This chapter has been published as:

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The published version of the paper has been presented as Appendix I. The quality assessment of quantitative and qualitative studies and the PRISMA checklist are presented as Appendix J, K and L respectively. PloS One is an open access journal, therefore this manuscript was published as an open access article which can be distributed under the terms of the Creative Commons Attribution License, provided the authors and source are cited.

3.1 Preface

Chapter Three presents a systematic review to summarise the current state of the literature. As the concept of recovery has been identified to incorporate both clinical and personal recovery views, longitudinal and qualitative studies on the experience of recovery from the perspectives of consumers, clinicians, family and carers were included in the review.

3.2 Abstract

Purpose: Longitudinal studies support that symptomatic remission from Borderline Personality Disorder (BPD) is common, but recovery from the disorder probably involves a broader set of changes in psychosocial function over and above symptom relief. A systematic review of literature on both symptomatic and personal recovery from BPD was conducted including the views of consumers, clinicians, family and carers.

Materials and Methods: A PRISMA guided systematic search identified research examining the process of recovery from BPD. Longitudinal studies with a follow-up period of five or more years were included to avoid treatment effects.

Results: There were 19 studies, representing 11 unique cohorts (1122 consumers) meeting the review criteria. There was a limited focus on personal recovery and the views of family and carers were absent from the literature. Rates of remission and recovery differ depending upon individual and methodological differences between studies. Data on symptomatic remission, recurrence and diagnosis retainment suggests that BPD is a stable condition, where symptomatic remission is possible and the likelihood of recurrence following a period of remission is low.

Conclusion: Symptomatic remission from BPD is common. However, recovery including capacities such as engaging in meaningful work was seldom described. Future research needs broader measures of recovery as a sub-syndromal experience, monitoring consumer engagement in meaningful vocation and relationships, with or without the limitations of BPD.

3.3 Introduction

Since the deinstitutionalisation of mental health services and the rise of the consumer movement, differences in the conceptualisation of recovery have been proposed in the literature (Jacobson & Greenley, 2001; Whitley & Drake, 2010). Recent recovery frameworks have adopted a dimensional approach where, the clearest divide between dimensions has been associated with clinical and personal notions of recovery (Davidson & Roe, 2007; Slade, 2009). Traditional notions of recovery have been clinically based, focused upon the remission of symptoms (or no longer meeting diagnostic criteria) and the return to previous levels of functioning (Davidson & Roe, 2007; Le Boutillier et al., 2011; Slade, 2009). Although Borderline Personality Disorder (BPD) has historically been viewed as an untreatable disorder, more longitudinal studies have suggested an upward trend towards remission (McGlashan, 1986; Paris & Zweig-Frank, 2001; Zanarini, Frankenburg, Reich, & Fitzmaurice, 2012) and improvements in levels of functioning (McGlashan, 1986; Plakun, Burkhardt, & Muller, 1985). The definitions for remission and reccurence in the literature were similar with high concordance, as they were determined by diagnostic criteria and interview measures. The predominant definition used for remision was no longer meeting the specified criteria for BPD and for recurrence was meeting diagnostic criteria following a period of achieving remission.

An increasing number of psychotherapeutic interventions have been developed specifically for the treatment of BPD. Concerns have been raised over the insufficient evidence available to demonstrate the broader efficacy of these interventions beyond symptom change (National Institute for Health Care Excellence, 2009; Leichsenring, Leibing, Kruse, New, & Leweke, 2011; McMain et al., 2009). Randomised control trials comparing identifiably different manualised treatments for BPD have found similarities in the rates of improvement despite

purported differences in approach (National Health and Medical Research Council, 2012). Given that psychotherapy is the recommended first line intervention for the treatment of BPD, strengthening interventions may improve consumer outcomes (Anthony, 1993; Leamy et al., 2011).

Measuring functional outcomes and symptom remission is important, yet these measurements do not always take into consideration the broader views or lived experiences of consumers or differences in trajectory between individuals. Traditionally in the mental health literature, consumers have challenged this clinical conceptualisation in favour of a holistic view of mental health. 'Personal recovery' (or consumer driven definitions of 'recovery') has been widely described within the literature (see Davidson, & Roe, 2007; Horn et al., 2007; Lariviere et al., 2015; Slade, 2009). This review adopts the definition most widely accepted within the recovery literature. Personal recovery is defined as 'a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness.' (Anthony, 1993, p527). Given that most clinical trials are only focused on symptom improvement, and reviews of this literature are available, we chose to review studies that have taken a longer perspective (five years or greater) on the journey of people with BPD. The inclusion criteria of 'five years or great' was applied to avoid the inclusion of treatment studies which may utilise a shorter follow-up period, and therefore did not examine the natural course of BPD. In this way we have ensured that we focus our review on longer term outcomes where notions of recovery are likely to become more important. The use of the 'five years of greater' criteria was a decision made by the research team in consultation with experts in personality disorder and longitudinal design. Given differences in measures and cut-off scores used in the included studies to determine diagnostic status in individual, the use of a longer follow-up period allowed for a more conservative estimate of outcomes.

The lived experience of consumers diagnosed with BPD has attracted some attention in the literature, where research has discussed the impact of the BPD diagnosis (Katsakou et al., 2012; Nehls, 1999; Straker & Waks, 1997), the stigmatised nature of the disorder (Katsakou et al., 2012; Nehls, 2001; Straker & Waks, 1997), experiences with treatment (Nehls, 2001; Perseius, 2003), and consumers' experiences of the disorder (Briand-Malenfant, 2012; Miller, 1994; Nehls, 1999). There is no review examining the longer term outcomes of people with BPD. The present study aims to systematically review the literature on longer-term clinical and personal recovery from BPD through the perspectives of consumers, clinicians, family and carers. A comparison between recovery in BPD compared to other mental health disorders will also be explored. Through this, gaps in the literature and future research directions will be identified.

3.4 Materials and Methods

The review followed the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) statement (Moher, 2009) in reporting findings of the review. A predetermined protocol outlining methods of data searching, inclusion criteria and data extraction method used was registered on the International Prospective Register of Systematic Reviews (PROSPERO, registration number: CRD42015019838).

Articles included for review were identified using a three step process: 1) searching electronic databases, 2) reference list searching and 3) identifying articles known to researchers which complied with the inclusion criteria. Electronic databases searched included; PsychINFO, Psychological and Behavioural Collection, PubMed, Scopus and Web of Science. The same search strategy was used in all databases and included; [(Consumer OR Client OR Patient OR Service User) AND/OR (Clinician OR Therapist) AND/OR (Family OR Carer OR Significant Other)] AND [(Borderline Personality Disorder OR BPD) AND

(Qualitative OR Longitudinal) AND (Remission OR Recovery OR Hope OR Psychotherapy OR Therapy OR Client Cent* OR Resilience OR Social Support OR Social Inclusion OR Wellbeing OR Rehabilitation OR Meaning)]. Searches were limited to articles published in English and to research conducted with humans.

Reference lists of sources included in the review were scanned to further identify additional sources. This process was completed twice, firstly on sources identified from the initial electronic database search and secondly on articles identified from the first reference list search. Known sources, particularly recently published articles not identified by the electronic search or reference list search, which complied with the inclusion criteria, were included in the review. One researcher conducted the search and identified articles for inclusion in the review. Articles were initially assessed via their title and abstracts and then in full. Articles eligible for inclusion in the review were checked with an expert in personality disorders. Disagreements were resolved by consensus. One reviewer then extracted data from the included studies, which was checked by a second reviewer. Location of the study, sample, aims, inclusion criteria, data collection methods and tools, major findings and limitations were extracted and coded. To reduce the risk of bias, all articles included in the review were assessed for quality as described below. Qualitative and longitudinal sources were assessed separately using quality assessment tools specific to the methodology.

A predetermined inclusion and exclusion criteria was used to identify articles relevant to the research question. All included studies were required to have BPD as the main disorder under examination and be published in English. Where more than one disorder was examined in an individual study, it was only included in the review if BPD was the main focus of investigation and the other disorders acted as either a comparison group or control group. For example studies which examined the relationship between BPD and other personality

disorders was included in the review, so long as they met the other inclusion criteria. As the review aimed to examine the long-term outcomes of BPD, the review was interested in the symptomatic remission and consumer understandings of recovery. All perspectives from consumers, families, carers or clinicians were included in the review to gain a holistic view of recovery. Studies were included in the review if the participants described were within the community or inpatient settings at the time of data collection. This however, excludes all patients from the forensic system with the BPD diagnosis, including consumers in forensic psychiatric inpatient units and their carers and clinicians. This is due to the association between BPD and antisocial personality disorder which is prevalent within forensic settings and not the focus of the present review.

The mention of treatments received by patients within individual studies did not lead to its exclusion, however studies that were conducted with intention to evaluate the effectiveness of specific interventions or comparative treatment studies were excluded from the review. This was due to the aim to examine the long-term outcomes of BPD rather than study treatment effects or treatment trial implementation. Due to this treatment trials with a follow-up period of less than five years were also excluded. No restrictions were placed on the publication period.

The quality of longitudinal studies was assessed using a criteria adapted from Kuijpers and colleagues (2004) and Luppino and colleagues' (2010) review which evaluated domains including study population, baseline and follow-up measures and the measurement tools used, and has been widely used in previous research (for example Kuper, Lingard, & Levinson, 2008; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005). Items on the quality assessment criteria were scored using a plus, minus or question mark. A score of one was given to items rated as a plus and a score of zero was given to items rated as a minus or

question mark (See Appendix J). Studies were required to score at least six out of ten quality criteria in order to be included for review (Kuijpers et al., 2004; Luppino et al., 2010). Included studies scored highly on all domains assessed, however common domains that studies did not fulfil included having less than 75% of the initial cohort included in the study, having a dropout rate greater than 20% at follow-up, and diagnosing study participants with BPD without a clinical interview.

Quality of qualitative studies was assessed using a combination of assessment tools which examined credibility and rigour. The quality assessment criteria developed by Kuper, Lingard and Levinson (2008) assessed domains including the sample, data collection, analysis, transferability of results, ethical consideration and coherence of the study. Studies were ranked as 'very good', 'good', 'acceptable' or 'unclear', where an 'acceptable' or above score in four of the six domains was required in order to be included in the review. Qualitative studies were also classed on the hierarchy of qualitative evidence (Daly et al., 2007), which ranged from single case studies (least likely to produce good evidence for practice), descriptive studies, conceptual studies and generalisable studies (strongest) (See Appendix K). These methods of appraising qualitative research have been used in a number of studies (Siabani, Leeder, & Davidson, 2013; Stack, Sahni, Mallen, & Raza, 2013; Swennen et al., 2013). All domains assessed from the included qualitative articles was ranked 'acceptable' or higher, except in one domain in Lariviere and colleagues' (2015) where it was unclear if ethical issues were considered.

A thematic synthesis approach adapted from Thomas and Harden (2008) was used to identify key themes from included studies. A three step process involving: 1) line by line inductive coding of the results section of included studies, 2) translation of codes into descriptive themes, and 3) the development of analytical themes was used. Multiple codes were used to

encapsulate the meaning and content of findings in line by line coding. Descriptive themes were developed through translating codes. The synthesis of descriptive themes to analytical themes was guided by the research question of the review which incorporated the theoretical conceptualisations of recovery. The trustworthiness of the data was ensured through consistent discussion amongst the research team about emerging codes and themes, where discrepancies were resolved via consensus. The quality assessment of longitudinal and qualitative studies was conducted by one researcher (FN) and then checked by an expert in personality disorders (BG).

3.5 Results

3.5.1 Search Results

A total 697 sources was identified through electronic database searching (n=426) and identifying additional sources (n=271). Following the application of limits (to the English language and research conducted with humans) and the removal of duplicates, 514 sources were screened through their title and abstract. A total of 479 sources were excluded from the review, as they did not meet the inclusion criteria. Of the remaining 35 sources, 16 sources were excluded due to sources not being empirical in nature (n=1), not related to recovery or remission (n=12), follow-up period in longitudinal studies was less than five years (n=2) or the methodology was not longitudinal or qualitative in nature (n=1). The remaining 19 sources were included for review, consisting of 16 longitudinal studies and three qualitative studies (See Figure 1).

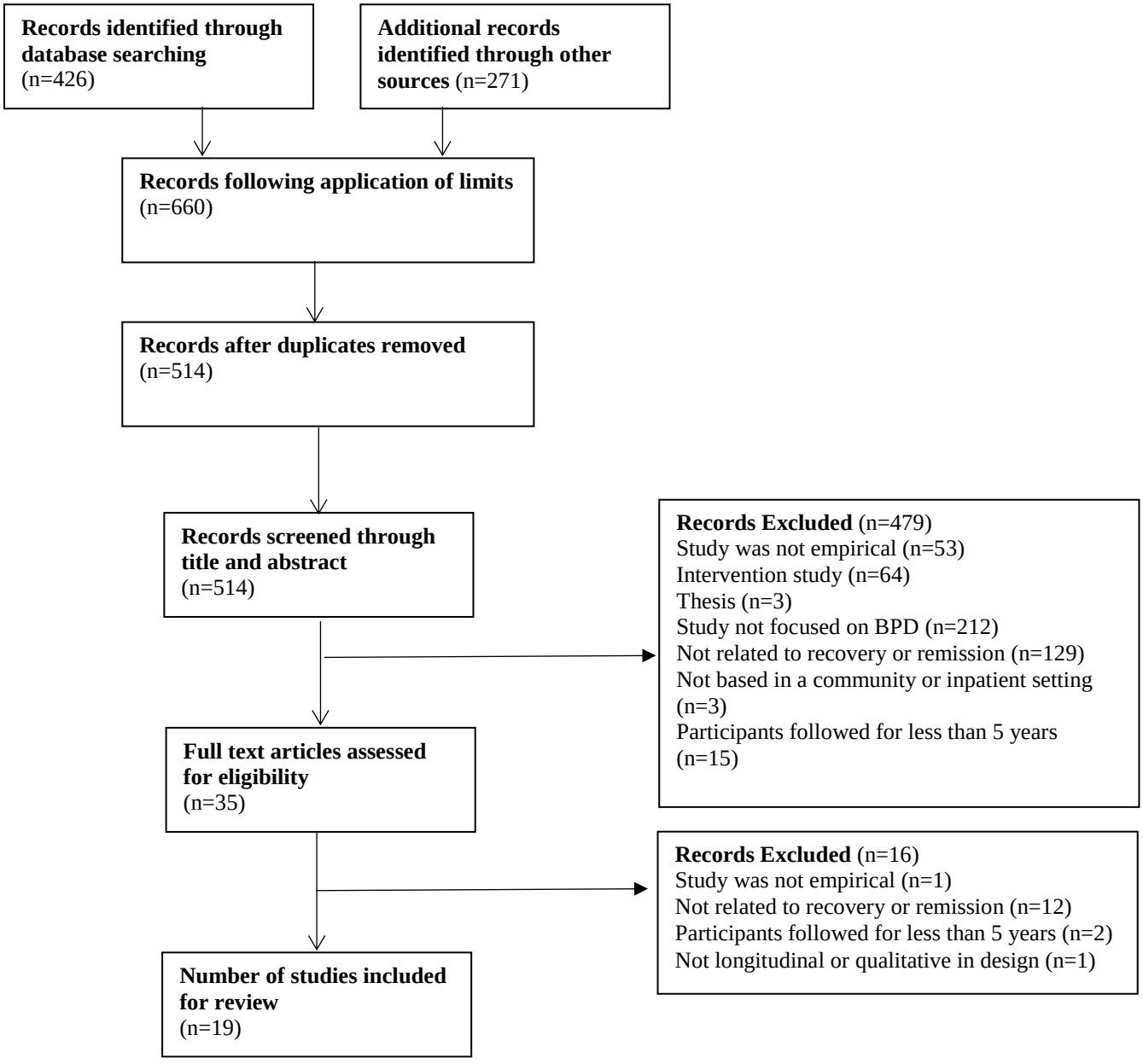

Figure 1: PRISMA flowchart for the selection of studies included in the systematic review

3.5.2 Study Characteristics

3.5.2.1 Overview of quantitative studies

Of the 19 included studies, 16 studies were longitudinal in nature (See Table 2). The range of publication years lead to differences in the method used to assess patients for diagnosis of BPD where chart analysis (n=9) (McGlashan, 1985, 1986; Paris & Zweig-Frank, 2001; Paris, Brown & Nowlis, 1987; Plakun, 1991; Plakun et al., 1985; Pope, 1983; Stone, 1990; Stone, Hurt & Stone, 1987) and clinical interviewing (n=7) (Gunderson et al., 2011; Links, Heslegrave, Mitton, Van Reekum, & Patrick, 1995; Links, Heslegrave & Van Reekum, 1998; McMain et al., 2009; Zanarini, Frankenberg, Hennen, J., Reich, & Silk, 2006; Zanarini et al., 2012; Zanarini, Frankenburg, Hennen & Silk, 2003; Zanarini, Frankenburg, Reich, & Fitzmaurice, 2010) was used. Studies predominately used the Diagnostic and Statistical Manual of Mental Disorders - Third Edition criteria (DSM-III; n=5) to determine the inclusion of participants and in assessing remission, recurrence or diagnosis retainment status, whilst others used the Diagnostic Interview for Borderlines (DIB; n=4), DSM Fourth Edition (DSM-IV; n=1), DIB and DSM-III-R (n=4) or the DSM-III and Gunderson and Kolb (1978) criteria (n=2). Several measures of functioning were used depending on when the study was conducted, these included the Health Sickness Rating Scale (HSRS; n=4), the Global Assessment Scale (GAS; n=4) and the Global Assessment of Functioning (GAF; n=5) although these are all highly similar. Three studies did not measure a participant's level of functioning. All quantitative studies met the quality appraisal criteria and all were included for review.

3.5.2.2 Overview of qualitative studies

From the 19 included studies, three studies were qualitative in methodology (Holm & Severinsson, 2011; Katsakou et al., 2012; Lariviere et al., 2015), which aimed to gain an understanding of the recovery process from BPD through the perspectives of consumers (See Table 2). Two studies were conducted in Europe and the other in North America. All studies were conducted using semi-structured interviews, however differed in analysis technique where one study analysed responses through a grounded theory approach (Perseius, 2003), whilst the remaining studies used thematic analysis (Holm & Severinsson, 2011; Lariviere et al., 2015). Articles represented different professional backgrounds including psychology, occupational therapy and nursing. All qualitative studies were appraised using the Kuper, Lingard and Levison (2008) guidelines and all were rated above the 'acceptable' standard. Studies were also ranked using the Daly and colleagues (2007) hierarchy of evidence were two studies were categorised as conceptual studies (Holm & Severinsson, 2011; Katsakou et al, 2012) indicating that theoretical frameworks guided the recruitment and analysis of results which reflected participant's views. The remaining study was categorised as a descriptive study (Lariviere et al., 2015) where the article described the participant's view in a practical rather than theoretical manner. All studies met the minimum quality criteria and were included for review.

Table 2. Characteristics of included studies

Source	Study type	Location	Sample	Aim	Inclusion criteria	Data collection and measures used	Findings	Limitations
Pope et al., 1983	Longitudinal (follow-up range: 4 – 7 years)	United States	Patients with Borderline Personality Disorder (n=33)	To examine the validity of the BPD diagnosis and compare BPD to DSM-III schizophrenia, MDD and other PDs.	Inpatient at McLean Hospital between 1974 and 1977 Aged over 18 years Based on hospital records received a score of 6 or more on the DIB Met DSM-III diagnostic criteria for BPD	DSM-III DIB	Differences between patients with BPD, BPD and MDD and schizophrenia were identified. BPD and schizophrenia diagnosis was stable, however the BPD diagnosis was less stable in patients with BPD and MDD. Comorbidity with MDD predicted better functioning and symptom remission.	The study had a small sample size and over half of the sample also met criteria for DSM-III Major Affective Disorder.
McGlashan, 1985	Longitudinal (follow-up average 15 years after discharge, ranged between 2 – 32 years)	United States	Patients with BPD (n=81)	To identify outcome predictor variables for BPD and examine the applicability of schizophrenia predicator variables for BPD.	Without organic brain syndrome Between 16 and 55 years at admission Treated at Chestnut Lodge for at least 30 days	Diagnosis assigned through transposition of medical records to the chart abstract. Based on 56 demographic/predictor variables and 49 signs and symptom variables. Standard Follow-up Interview Battery and Extended Interview Follow-up Battery (see Feighner, 1972)	Diagnosis of BPD remained stable at follow-up with approximately 50% of patients experiencing moderate levels of symptoms. Patients with BPD accessed treatment at the same rate as patients with UNI but at a lower rate than patients with schizophrenia. Patients with BPD were more likely to be engaged in vocation and had higher global outcomes.	The study used chart analysis to identify potential patients, however more than 20% of participants dropped out of the study at follow-up. The study does not discuss which treatments participants have engaged in.
Plakun et al., 1985	Longitudinal (follow-up on average 13.6 years	United States	Study draws from a larger sample (N=237) however, reports on patients with 'pure' BPD (n=43), BPD and SPD (n=6), BPD and SDPD (n=5), BPD and MDD (n=9), schizophrenia (n=19), MDD (n=24), SPD (n=13),	To examine the functioning of patients with BPD or SPD compared to schizophrenia, MDD and other disorders.	Admitted to Austen Riggs Centre for at least 2 months between 1950 and 1976	GAS	Patients with BPD had better levels of functioning than patients with schizophrenia, however no difference with patients with MDD. BPD and MDD group was found to be functioning worse than aggregated BPD group which is inconsistent with the previous literature.	Differences in sample size between groups in the study, reliability of results is questionable.

Source	Study type	Location	Sample	Aim	Inclusion criteria	Data collection and measures used	Findings	Limitations
McGlashan, 1986	Longitudinal (follow-up on average 15 years, range = 2-32)	United States	Patients with BPD (n=81), Schizophrenia (n=163) and Unipolar affective disorder (n=44)	To examine the long term course and outcomes of individuals diagnosed with BPD compared to patients with schizophrenia or UNI.	Patients discharged from Chestnut Lodge between 1950 and 1975. A select number of non-discharged patients were also included Patients without organic brain syndrome Aged between 16 and 55 years Inpatient for a minimum of 90 days	Used Chart Abstract to re-diagnose patients using: BPD: DSM-III criteria; Gunderson and Kolb (1978) criteria for BPD Schizophrenia: New Haven Schizophrenia index; Feighner and colleagues criteria (1972); Research Diagnostic Criteria; DSM-III MDD and Schizotypal PD: DSM-III	Diagnosis of BPD remained stable over the follow-up period. Use of services was a similar rate in consumers with BPD and UNI but higher in patients with schizophrenia. Compared to patients with UNI or schizophrenia, patients with BPD have better levels of vocational engagement, global outcomes (hospitalisation and symptoms experienced). Full recovery was perceived as unachievable due to chronicity of disorder and individual character.	The study used chart analysis to identify potential patients, however more than 20% of participants dropped out of the study at follow-up. The study does not discuss treatments participants have engaged in.
Paris, Brown & Nowlis, 1987	Longitudinal (follow-up for an average of 15 years)	Canada	Patients with BPD (n=100)	To examine long term outcomes of patients with BPD being treated in a general hospital	Diagnosis of BPD or retrospective diagnosis of BPD	DIB HSRS Schedule for Follow-up of Borderline Patients	Quarter of patients still met criteria DIB for BPD. Patients at follow-up was functioning better however still had some difficulties. Work history, relationships and family adjustment was at a comparable level to outpatients. Social functioning improved due to less chaotic relationships, however dysphoria, younger age at diagnosis and family history predicted worse outcomes.	Chart review was used to identify patients meeting criteria for BPD. No comparison score for HSRS at baseline. Unable to determine significance of change at follow-up. Limited patient demographic information provided. Effects of treatment unclear from data.
Stone, Hurt & Stone, 1987	Longitudinal (follow-up at 16 years)	United States	Patients diagnosed with BPD (n=205)	To describe the global outcomes of patients with BPD	Patients admitted into New York State Psychiatric Institute between 1963 – 1976	GAS	Consumers with BPD had higher levels of functioning and most reached a 'clinically well' stage compared to patients with schizophrenia. Patients with comorbid MDD had higher levels of functioning than patients with BPD only. Similar suicide rates in BPD and schizophrenia groups.	Baseline data on functioning scores is not provided and the types of treatment received by patients is not clear

Source	Study type	Location	Sample	Aim	Inclusion criteria	Data collection and measures used	Findings	Limitations
Stone, 1990	Longitudinal (follow-up at 16 years)	United States	Patients diagnosed with BPD and schizophrenia	To describe the global outcomes of patients with BPD	Admitted to the General Clinical Service at New York State Psychiatric Institute for at least 3 months	Chart analysis using DSM-III criteria and guidelines of BPD from Kernberg (1976) GAS	Patients with schizophrenia were more likely hospitalised during the follow-up period compared to patients with BPD, similarly observed in rates of institutionalised care during follow-up. More patients with BPD were able to work at least 50% of the follow-up, however patients with schizophrenia were identified as most 'handicapped'.	Use of chart review to diagnose patients. Does not discuss remission, recurrence or retainment rates
Plakun, 1991	Longitudinal (follow-up on average 13.6 years	United States	Study draws from a larger sample, however reports on patients with BPD only (n=33)	To identify predictors of outcome in BPD.	Admitted to Austen Riggs Centre for at least 2 months between 1950 and 1976 Minimal comorbidities with affective disorder, substance abuse or other PDs.	GAS	Strongest predictors of outcome in patients with BPD were associated with demographic variables. Symptoms of personality disorder were identified to predict poorer social and vocational prognosis at follow-up. Poorer vocational outcomes were also predicted by experiences of chronic emptiness or boredom. Did not find the link between higher IQ and better outcomes.	Limited sample of patients with BPD.
Links, Heslegrave, Mutton, Van Reekum & Patrick, 1995	Longitudinal (follow-up at 7 years)	Canada	Patients with borderline psychopathology (n=88) or traits (n=44)	Aimed to examine the relationship between borderline psychopathology and other clinical disorders at follow-up	Aged between 18 and 65 at admission Inpatient in acute psychiatric setting Clinical diagnosis of BPD or at least 3 of 7 borderline characteristics as described by Gunderson and Kolb (1978)	SADS RDC DIB	At follow-up 47.4% of patients retained the BPD diagnosis. Persistent group more likely to be diagnosed with other clinical disorders compared to the remitted group, however no differences in the number of depressive episodes between these groups were identified. 'New' BPD group had higher episodes of depression. Borderline psychopathology at baseline was predictive of other clinical disorders at follow-up.	More than 20% of participants dropped out of the study which lead to an over proportion of females in the sample. Types of treatment received by participants is unclear.

Source	Study type	Location	Sample	Aim	Inclusion criteria	Data collection and measures used	Findings	Limitations
Links, Heslegrave & Van Reekum, 1998	Longitudinal (follow-up at 7 years)	Canada	Patients diagnosed with Borderline Personality Disorder (n=88) and patients with borderline traits (n=44)	Aimed to examine the persistence of BPD and occurrence of other personality disorders at follow-up. To identify the predictive value of personality disorder psychopathology in determining severity of BPD and other PDs at follow-up.	Aged between 18 and 65 at admission Inpatient in acute psychiatric setting Clinical diagnosis of BPD or at least 3 of 7 borderline characteristics as described by Gunderson and Kolb (1978)	SADS RDC DIB GAS SIDP-R	At follow-up 47.4% of patients retained BPD diagnosis and patients with persistent BPD had a higher incidence of other PDs. Persistent and 'new' groups had a similar number of comorbid PDs. DIB level of psychopathology at baseline was predictive of borderline psychopathology and self-defeating behaviours at follow-up.	More than 20% of participants dropped out of the study which lead to an over proportion of females in the sample. Type of treatment received by participants is unclear.
Paris & Zweig-Frank, 2001	Longitudinal (follow-up on average 27 years)	Canada	Patients with BPD (n=64)	To follow-up patients to examine whether symptomatic relapses occur during later middle age.	Part of the pervious follow-up phase (Links et al., 1995)	DIB-R SCID GAF SCL-90 SAS-SR	Significant decrease in the prevalence of BPD and the number of criteria still met in the sample. No significant differences in functioning over the baseline and follow-up period, however attributed this to use of different scales and it is proposed that there is a limit on the level of improvement in patients with BPD.	Chart review was used to identify patients meeting criteria for BPD.
Zanarini, Frankenburg, Hennen & Silk, 2003	Longitudinal (6 year follow-up)	United States	Patients with BPD (n=290)	To examine the six year course of syndromal and sub-syndromal BPD.	Aged between 18 and 35 years IQ of 71 or higher No history of an organic condition, schizophrenia, schizoaffective disorder or Bipolar I Fluent in English	SCID DIB-R Background Information Schedule	Remission from BPD was common and increased with every follow-up phase. At two year follow-up, 34.5% of consumers had achieved remission. Over the six year period, 73.5% of consumers had experienced remission. Only 5.9% of consumers experienced recurrence.	Participants were recruited from an inpatient setting and may not be representative of the general population. Treatment engagement is unclear.

Source	Study type	Location	Sample	Aim	Inclusion criteria	Data collection and measures used	Findings	Limitations
Zanarini, Frankenberg, Hennen, Reich & Silk, 2006	Longitudinal (based on 10 year follow-up data)	United States	Patients with BPD (n=249)	To determine which variables best predict remission from BPD	Aged between 18 – 35 years IQ above 71 No history of schizophrenia, schizoaffective disorder, bipolar I or organic conditions Fluent in English	Semi-structured interviews Background Information Schedule SCID DIB-R DIPD	The amount of time for remission was found to be predicted by younger age, no prior hospitalisations, no history of child sexual abuse, low levels of verbal, physical and emotional abuse and limited witnessing of violence. Higher levels of childhood competence and the absence of family history of mood or substance disorder decreased the time to remission. Not having comorbidities with PTSD or anxious cluster personality disorders, having normal personality traits and a good vocational record decreased time to remission	Patients were recruited from an inpatient setting which may influence functioning scores and may not be representative of the general population. Difficulties with comparing GAF scores as scores at baseline and follow-up were not presented. The types of treatment consumers engaged in during the follow-up period were unclear.
Zanarini, Frankenberg, Reich & Fitzmaurice, 2010	Longitudinal (10 year follow-up)	United States	Patients with BPD (n=249)	Continuation of the McLean Study of Adult Development which aimed to examine the rates of symptom remission, recovery and sustained recovery in BPD.	Aged between 18 – 35 years IQ above 71 No history of schizophrenia, schizoaffective disorder, bipolar I or organic conditions Fluent in English	Semi-structured interviews Background Information Schedule SCID DIB-R DIPD	Symptomatic remission was achieved by the majority of participants (98%) where 86% of participants were able to maintain for a four year period. Recovery was identified to be more difficult to achieve, however was table once attained. Difficulties with functioning still observed at 10 years.	Patients were recruited from an inpatient setting which may influence functioning scores and may not be representative of the general population. The types of treatment consumers engaged in during the follow-up period was unclear.
Gunderson et al., 2011	Longitudinal (10 year follow-up)	United States	Three study groups; BPD (n=175), cluster C PD (n=312) and MDD (n=95)	Compare course of BPD (symptoms and functioning) with other PDs and MDD	Participants had to be 18-45 years old who have received psychiatric care and met criteria of screening tools including PSQ, DIPD-IV, PAF, SNAP	DIPD DSM-IV GAF Same measures used at baseline, 6 months and 12 months and 2,4,6,8 and 10 years.	Significant proportion of patients (91%) achieved remission and relapse was less common in BPD compared to other disorders. Patients with BPD had poorer levels of functioning compared to patients with OPD and MDD at follow-up. Older age predicted poorer functioning and higher levels of education predicted higher levels of functioning. Engagement in vocation and marital status improves over time.	Study does not provide information on the treatments received by consumers and does not take into consideration the views of consumers

Source	Study type	Location	Sample	Aim	Inclusion criteria	Data collection and measures used	Findings	Limitations
Holm & Severinsson, 2011	Qualitative	Norway	Thirteen female service users	To identify how the recovery process leads to changes in suicidal behaviour	Participants had to be female with a diagnosis of BPD	Thematic analysis of semi-structured interviews	Recovery process facilitated changes to suicidal behaviours, by increasing consumers' desire to take responsibility for self, being understood and refusing to be defeated by the disorder. Self-development assisted with developing trust and a sense of safety with self and others.	Only the perspectives of female consumers were considered and the study had a small sample size
Katsakou et al., 2012	Qualitative	United Kingdom	Consumers with BPD (n=48)	To gain understanding into the goals and aspirations of service users to better understand views of recovery	Individuals that were over 18 years of age, diagnosis of BPD and history of self-harm (self –injurious behaviour, overdose or suicide attempts)	Semi-structured interviews Grounded theory and thematic analysis	Consumer recovery goals were associated with improving symptoms of BPD and engaging in meaningful activities. However consumers did not believe specialised treatments for BPD prioritised their goals. Level of recovery fluctuated within participants where most acknowledged that they had improved but not fully recovered. This led to questions of whether 'recovery' encapsulated their experience.	Limited to perspectives of consumers. Study conducted in one location.
Zanarini, Frankenberg, Reich & Fitzmaurice, 2012	Longitudinal (follow-up at 16 years)	United States	Patients with BPD (n= 231)	To determine the time needed to reach and the stability of symptomatic remission and recovery in patients with BPD	Aged between 18 – 35 years IQ above 71 No history of schizophrenia, schizoaffective disorder, bipolar I or organic conditions Fluent in English	Semi-structured interviews Background Information Schedule Structured Clinical Interview for DSM-III-R Axis I disorders Revised Diagnostic Interview for Borderlines Diagnostic Interview for DSM-III-R Personality Disorders	Symptomatic remission for a two year period was achieved by 99% of participants. Compared to other Axis II disorders, BPD had a slower remission rate. Recovery occurred slowly and there was a higher risk of relapse compared to other disorders. Vocational participation impacted upon obtaining recovery.	Patients were recruited from an inpatient setting which may influence functioning scores and may not be representative of the general population. Difficulties with comparing GAF scores as scores at baseline and follow-up were not presented. The types of treatment consumers engaged in during the follow-up period are unclear.

Source	Study type	Location	Sample	Aim	Inclusion criteria	Data collection and measures used	Findings	Limitations
Lariviere et al., 2015	Qualitative	Canada	12 female service users from two BPD specialist services in Quebec, Canada.	To capture the recovery experiences of women from BPD through analysis of experiences through the PEO model.	Participants had to be female, diagnosed with BPD, be aged between 18 and 65 years and had completed 2 years of treatment for BPD in a specialised service.	Creation of a picture collage, two semi-structured interviews and review of medical records. Thematic analysis of semi-structured interviews	Consumers associated recovery with personal development, greater emotional control, assertiveness, interpersonal relationships, having meaningful roles/vocation and letting go of the past and looking towards the future. It is suggested that the concept of wellbeing may better encapsulate the experiences of consumers than 'recovery'.	Small sample size and only included the perspectives of female consumers. Analysis completed in line with PEO model, may have missed perspectives that did not fit within the categories

BPD: Borderline Personality Disorder; **DIB:** Diagnostic Interview for Borderlines; **DIB-R:** Revised Diagnostic Interview for Borderlines; **DIPD-IV:** Diagnostic interview for DSM-IV Personality Disorders; **DSM-III:** Diagnostic and Statistical Manual for Mental Disorders – Third Edition; **DSM-IV:** Diagnostic and Statistical Manual for Mental Disorders – Fourth Edition; **GAF:** Global Assessment of Functioning; **GAS:** Global Assessment Scale; **HSRS:** Health-Sickness Rating Scale; **IQ:** Intelligence Quotient; **MDD:** Major Depressive Disorder; **OPD:** Other Personality Disorder; **PAF:** Personality Assessment Form; **PD:** Personality Disorder; **PEO:** Person-Environment-Occupation; **PSQ:** Personality Screening Questionnaire; **RDC:** Research Diagnostic Criteria; **SADS:** Schedule for Affective Disorders and Schizophrenia; **SAS-SR:** Social Adjustment Scale; **SCID:** Structured Clinical Interview for DSM-III-R Axis I Disorders; **SCL-90:** Symptom Check List-90; **SDPD:** Schizoid Personality Disorder; **SIDP-R:** Structured Interview for DSM-III-R Personality; **SNAP:** Schedule for Non-adaptive and Adaptive Personality; **SPD:** Schizotypal Personality Disorder; **UNI:** Unipolar Affective Disorder.

3.5.3 Sample Characteristics

To avoid duplication of participants, longitudinal studies that had more than one published follow-up article were not all included in the sample characteristics. In these cases, only the baseline study of the specific cohort was counted. Overall, the 19 included studies represented 11 unique cohorts of participants (eight cohorts from included longitudinal studies and three cohorts from included qualitative studies), equating to a total of 1122 individual consumers with BPD. Consumers represented in the included studies were predominately female (72.5%) from a Western background (84.6%) with an average age of 30.3 years. Most were never married (63%) and were not engaged in a vocation (64.9%).

3.5.4 Main Findings from Quantitative Studies

The findings from the quantitative studies were categorised into three major themes: 1) remission, recurrence and diagnosis retainment rates, 2) level of functioning, 3) predictors of outcomes, and 4) differences between BPD and other disorders.

3.5.4.1 Remission, Recurrence and Diagnosis Retainment Rates

Definitions used to identify remission, recurrence and diagnosis retainment rates were determined by the definitions used by the included studies. As such remission rates represented patients who had previously met the specific diagnostic criteria for BPD but did not meet criteria at follow-up. Similarly, recurrence refers to patients who had previously achieved a state of remission, however experience symptoms meeting the diagnostic cut-off at follow-up. Diagnosis retainment was defined and represented by patients who met diagnostic criteria during one follow-up wave and continued to meet criteria at the next follow-up wave, thus retaining a diagnosis of BPD.

The follow-up period of studies discussing remission, recurrence, and diagnosis retainment ranged between 4 and 27 years. Data on remission rates were available in five cohorts (representing nine studies) (Gunderson et al., 2011; Links et al., 1995; Links, Heslegrave, & Van Reekum, 1998; Paris, & & Zweig-Frank, 2001; Paris, Brown & Nowlis, 1987; Pope, 1983; Zanarini et al., 2012; Zanarini, Frankenburg, Hennen & Silk, 2003; Zanarini, Frankenburg, Reich & Fitzmaurice, 2010), where rates ranged between 33-99% of patients. Table 3 shows the five studies and includes the follow-up timeframe the proportion in remission. Reccurence rates were avaliable for two cohorts (representing four studies) (Gunderson et al., 2011; Zanarini et al., 2012; Zanarini, Frankenburg, Hennen & Silk, K.R., 2003; Zanarini, Frankenburg, Reich & Fitzmaurice, 2010), ranging between 10-36% of patients,. Table 4 shows the recurrence rates and follow-up duration. Retainment rates were available for four cohorts (representing six studies) (Gunderson et al., 2011; Links et al., 1995; Links, Heslegrave & Van Reekum, 1998; Paris & Zweig-Frank, 2001; Paris, Brown & Nowlis, 1987; Pope, 1983) ranging between 7.8-66.7% of patients as shown in Table 5.

Table 3. Rate of remission from BPD across five cohorts representing 585 participants

Cohort	Sources	Remission Rates		
		Sample Size	**Remission Proportion**	**Follow-up in Years**
1	Pope et al., 1983	27	33.3%	4 - 7
2	Links et al., 1995 Links et al, 1998	88	52.6%	7
3	Paris & Zweig-Frank, 2001 Paris et al., 1987	64	92.2%	27
4	Gunderson et al., 2011	175	85%	10
5	Zanarini et al., 2003 Zanarini et al., 2010 Zanarini et al., 2012	231	99%	16

Table 4. Rate of recurrence from BPD across two cohorts representing 406 participants

Cohort	Sources	Recurrence Rates		
		Sample size	**Recurrence Proportion**	**Follow-Up in Years**
4	Gunderson et al., 2011	175	21% (following 12 months of remission) 11% (following of 10 years remission)	10
5	Zanarini et al., 2003 Zanarini et al., 2010 Zanarini et al., 2012	231	36% (following 2 years of remission) 10% (following 8 years of remission)	16

Table 5. Rate of diagnosis retainment from BPD across four cohorts representing 354 participants

Cohort	Sources	Diagnosis Retainment Rates		
		Sample size	**Retainment Proportion**	**Follow-Up in Years**
1	Pope et al., 1983	27	66.7%	4-7
2	Links et al., 1995 Links et al, 1998	88	47.4%	7
3	Paris & Zweig-Frank, 2001 Paris et al., 1987	64	7.8%	27
4	Gunderson et al., 2011	175	9%	10

3.5.4.2 Level of Functioning

Most longitudinal studies examined the level of functioning of patients within their cohorts. All functioning scales used in the included studies (HSRS, GAS and GAF) are revisions of the HSRS. Due to similarities across the scales, all ratings of functioning were pooled together to be representative of all included studies in the review. Overall, the findings indicate that despite substantial increases in functioning in patients with BPD, this level of functioning is still indicative of ongoing difficulties.

Baseline functioning ratings were provided by three studies (Gunderson et al., 2011; Plakun et al., 1985; Zanarini, Frankenburg, Hennen & Silk, 2003), representing 519 patients. Aggregated baseline functioning ratings resulted in an average score of 42 (range= 35-53), indicating that patients experienced serious symptoms and serious limitations in functioning (APA, 2000). Follow-up patient functioning was rated in six studies (Gunderson et al., 2011; McGlashan, 1986; Paris & Zweig-Frank, 2001; Paris, Brown & Nowlis, 1987; Plakun et al., 1985; Stone, Hurt & Stone, 1987), representing 679 patients. Despite differences in the length of follow-up, the average length of follow-up was 16 years (range= 10-27 years). Aggregated functioning scores at follow-up resulted in an average score of 63 (range=57-67). Patients were considered functioning well, however experienced mild symptoms and continuing difficulties with vocational functioning (APA, 2000). The change between baseline (42) and follow-up (63) functioning scores was substantial (Endicott, Spitzer, Fleiss, & Cohen, 1976).

3.5.4.3 Predictors of Outcomes

Seven studies examined variables that were predictive of outcomes (Gunderson et al., 2011; Links et al., 1995; McGlashan, 1985; Paris, Brown & Nowlis, 1987; Plakun, 1991; Zanarini, Frankenburg, Reich, & Fitzmaurice, 2010). Being diagnosed at a younger age, without

experiences of childhood sexual abuse or a family history of substance abuse predicted a faster rate of recovery (Zanarini, Frankenberg, Hennen, Reich & Silk, 2006). This was exemplified by findings that suggest familial experiences, such as substance abuse, history of mental illness and divorce, were predictive of negative outcomes (McGlashan, 1985; Plakun, 1991). Discrepancies however arose over the protective ability of being diagnosed at a younger age and having higher levels of educational attainment and intelligence, as these were not replicated across studies (Gunderson et al., 2011; McGlashan, 1985; Paris, Brown & Nowlis, 1987; Plakun, 1991).

Illness manifestation variables were identified to be the strongest predictors of global outcomes in patients with BPD, however discrepancies in the predictive ability of the illness course, admission index, demographic and background variables were identified. Meeting Gunderson and Kolb's (1978) criteria for BPD, experiencing personality disorder traits or affective symptomatology with dysphoric features was associated with poorer outcomes, however lower levels of psychosocial stress was a protective factor (McGlashan, 1985; Paris, Brown & Nowlis, 1987). Clinical indicators of faster rates of remission were associated with personality traits including low neuroticism, high agreeableness and the absence of anxious cluster personality disorders (Zanarini, Frankenberg, Hennen, Reich & Silk, 2006). Hospitalisations were predictive of the illness course where the length of prior admissions predicted the length of future admissions (Plakun, 1991). However, the predictive ability of hospitalisations on outcomes was inconsistent where some studies found that longer hospitalisations lead to poorer outcomes (McGlashan, 1985), whilst other studies found no difference (Plakun, 1991).

3.5.4.4 Differences between BPD and Other Disorders

Ten studies included in the review examined the association of BPD with other disorders. Common disorders examined included schizophrenia (n= 4), major depressive disorder (MDD, n=4) and other personality disorders (n=4). Differences in remission rates and functioning (as measured by standardised measures including the HSRS, GAS and GAF) were identified between disorders, such that patients with BPD had higher levels of functioning than patients with schizophrenia but not other personality disorders (Plakun et al., 1985; Stone, Hurt & Stone, 1987). Contradictory results with MDD were noted where some studies found patients with BPD functioned more poorly (Gunderson et al., 2011) whereas others found no difference (McGlashan, 1986). Results examining concomitant MDD with BPD were also contradictory such that some studies found poorer outcomes in patients with MDD and BPD compared to BPD alone (McGlashan, 1986). Rates of remission differed between the disorders such that BPD remitted at a slower rate compared to MDD and other personality disorders (Gunderson et al., 2011; Zanarini et al., 2010; 2012) but faster than schizophrenia (McGlashan, 1984). This suggests that patients with schizophrenia have poorer outcomes compared to patients with BPD; however it is unclear as to whether patients with MDD and other personality disorders have better outcomes than patients with BPD.

3.5.5 Main Findings from Qualitative Studies

Themes from the qualitative studies depicted consumer goals and factors that facilitated their recovery, however despite the ability to identify recovery or treatment goals, the conceptualisation of recovery was questioned. The consumer perceptions of their recovery fell into three broad themes; 1) active willingness to engage in the recovery journey, 2)

improving on clinical characteristics of BPD to facilitate change and 3) the conceptualisation of recovery.

3.5.5.1. Active Willingness to Engage in Recovery Journey

This theme was articulated across all qualitative studies where the desire for recovery was a prerequisite for change in other recovery dimensions (Holm & Severinsson, 2011; Katsakou et al., 2012; Lariviere et al., 2015). Studies identified that active willingness was initiated through the desire for meaningful roles, vocation and motivation to not be defeated by the disorder. Consumer engagement in a vocation or activities, such as completing daily tasks (e.g. paying bills), education, therapy or developing a career, facilitated change and provided a sense of achievement, competence and routine (Holm & Severinsson, 2011; Katsakou et al., 2012; Lariviere et al., 2015).

Having a sense of defiance to being defined or defeated by the disorder was identified by studies to promote consumer's willingness to engage in the recovery process (Holm & Severinsson, 2011). Gaining greater insight into BPD, through psychoeducation and therapy, facilitated recovery through the provision of a new language to communicate inner states and needs, in order to respond in an emotionally regulated manner and increase consumer's awareness of the functions of behaviour.

3.5.5.2. Improving on Clinical Characteristics of BPD to Facilitate Change

The ability to improve upon three clinical characteristics of BPD: 1) emotion regulation, 2) developing a sense of identity, and 3) improving interpersonal skills and relationships, were necessary in order to engage in other aspects of recovery.

The need for better 1) emotion regulation was reported by all studies, such that having a greater emotional experience facilitated recovery in other areas of consumer's lives. The ability to tolerate intense positive and negative emotions without the urge to engage in maladaptive behaviours was a priority. Similarly, despite the ability of self-harm to abate suicidal ideation, the reduction of self-harming behaviours promoted personal development in areas including identity formation and interpersonal relationships.

Developing 2) a sense of identity was an initial internal motivator for change that occurred through the acknowledgement of past experiences, developing a sense of self separate from others, and understanding the BPD diagnosis. The process of redefining identity commenced through a shift away from the passive and victim persona and the acceptance of past experiences to focus on the present (Katsakou et al., 2012; Lariviere et al., 2015). Although these were observed to reduce self-critical thoughts and promote self-acceptance, difficulties associated with the misunderstanding and misinterpretation of a consumer's intention by others was observed to hinder this process (Holm & Severinsson, 2011). For example, suicide attempts were identified as selfish and inconsiderate rather than fulfilling an emotion regulation function (Holm & Severinsson, 2011). Studies noted that the misinterpretations of others exacerbated the stigma perceived by consumers, perpetuating their negative perception of self, however gaining understanding into BPD provided behavioural insight and greater self-acceptance. Furthermore, developing a sense of identity separate from others was associated with the development self-confidence (Lariviere et al., 2015). The ability to express emotions and ask for needs to be met was facilitated through the development of assertiveness and was perceived as a sign of recovery.

Strengthening 3) interpersonal skills and relationships, was identified by studies to assist in widening a consumer's social network and provided opportunities to translate skills from

therapy (Holm & Severinsson, 2011; Katsakou et al., 2012; Lariviere et al., 2015). Positive benefits included learning to tolerate feelings of abandonment and rejection, and dealing with or ending dysfunctional relationships (Katsakou et al., 2012; Lariviere et al., 2015). Studies identified that having a sense of trust was essential in developing stronger relationships with others. However, this was paradoxical as a level of trust prior to entering into a relationship was required (Lariviere et al., 2015). A trusting relationship with the health system was particularly highlighted such that health professionals acted as an extended support network that could be drawn upon during times of need (Holm & Severinsson, 2011; Lariviere et al., 2015). However, stigma associated with the diagnostic label hindered trust formation and a consumer's ability to fully engage (Holm & Severinsson, 2011). Similarly, family and friends were also viewed to be an extended support network.

The development of interpersonal skills was noted by studies to assist in the improvement of the reflective capacity of consumers, allowing for greater insight into the impact of one's behaviour on others (Katsakou et al., 2012). This was identified as a particularly important skill as the ability to empathise with others during periods of distress was diminished (Holm & Severinsson, 2011).

3.5.5.3 The Conceptualisation of Recovery

The conceptualisation of recovery from BPD was discussed by two of the three qualitative studies (Katsakou et al., 2012; Lariviere et al., 2015). Studies discussed consumer's concerns as to whether the word accurately encapsulated their experiences. The dichotomous understanding of recovery was identified as an issue, as consumers viewed the synonymous conceptualisation of recovery and cure as unrepresentative of their experiences with BPD. Additionally, clinical implications were highlighted such that 'black and white' thinking may contribute to delays in help seeking. Alternative conceptualisations offered by studies

described consumer experiences as a “journey”, “progress” or “learning” (Katsakou et al., 2012, p6). This was particularly demonstrated within discussion about personal recovery goals where the multifaceted nature was emphasised. Recovery goals were associated with personal development (such as developing greater control over emotions and negative thinking patterns), developing interpersonal relationships and participation in activities and vocation (such as day to day activities, education or employment). Differences in the service defined understanding of recovery elicited frustration in consumers, where aspects of clinical recovery (including the reduction of symptoms) was emphasised. For example, the emphasis on specific behavioural change in some treatments may not always align to individual recovery goals (Katsakou et al., 2012). Difficulties with emotion regulation and interpersonal relationships were continual challenges for consumers meaning full remission may not be achieved. Katsakou and colleagues’ (2012) study described consumer’s recovery in stages from no progress to recovered.

3.6 Discussion

The review aimed to examine the clinical and personal conceptualisation of recovery from BPD through the perspectives of consumers, clinicians, family and carers. Despite the aim, most of the current literature to date was focused upon the clinical recovery of consumers with BPD. Clinician and observer ratings (e.g. of functioning) and consumer ratings (e.g. of symptoms) predominated. Although research into BPD has increased, limited attention has been placed on the lived experience of consumers and their support networks. The earliest article examining recovery from a consumer’s perspective was published as recently in 2011 and no articles on the recovery experiences from the perspective of clinicians, family and carers were identified. Overall, nineteen articles met the pre-determined inclusion criteria and were thematically synthesised, where four major findings emerged from the review.

3.6.1 Remission, Recurrence, and Diagnosis Retainment of BPD

Although rates of remission, recurrence and diagnosis retainment rates from BPD have been identified across a number of longitudinal studies, significant differences in how these concepts have been defined exist between studies. Remission rates ranged between 33-99%, whilst recurrence and retainment rates ranged between 10-36% and 7.8-66.7% respectively. Due to large variability within these rates, it is difficult to identify the exact proportion of patients who will experience remission, recurrence or diagnosis retainment in any given time period because of the use of various methodologies. These differences include; 1) the diagnostic tool used, 2) length of follow-up, 3) patient drop-out rate, 4) methods used to locate patients at follow up, and 5) the setting in which patients were recruited (inpatient or outpatient).

Differing cut-off requirements influences the proportion of patients that are considered remitted, experience recurrence, or those retaining the diagnosis. Patients in two cohorts (Links et al., 1995; Links, Heslegrave& Van Reekum, 1998; Pope, 1983) were assessed using the DIB however differed in cut-off requirements. Pope and colleagues'(1983) study endorsed a lower cut-off requirement (6 points) which may partially explain lower rates of remission and higher rates of diagnosis retainment within the cohort, compared to a relatively higher remission (7 point cut off requirement) and lower retainment rates found in Links and colleagues'(1983; 1995) cohort. The Pope and colleagues' study (1983) was also of severe multi-diagnostic cases seen before the first randomised controlled studies of treatment for BPD had been published.

The time period in which patients are followed up should also be considered, which in this review spanned between 4 and 27 years. Cohorts with longer follow-up periods, that is greater than 10 years (Gunderson et al., 2011; Paris, Brown & Nowlis, 1987; Paris & Zwieg-

Frank, 2001; Zanarini et al., 2003; Zanarini et al., 2010 Zanarini et al., 2012), have higher rates of remission, indicating that the experience of symptoms reduce with increasing age. This may be partially explained by previous research which has suggested that the experience of impulsivity in BPD reduces with increasing age (Stevenson, 2003), whilst other reasons proposed in the literature have included the effects of social learning over time and the avoidance of intimate relationships (Paris, 2002). The stability of the disorder has been highlighted in other studies, such that BPD criteria followed a similar reduction trend (Gunderson et al., 2011). Variability within recurrence rates was also associated with the time period as defined by researchers, where rates ranged between 10-36% (Gunderson et al., 2011; Zanarini et al., 2003; Zanarini et al., 2010 Zanarini et al., 2012). As expected, higher rates of recurrence (21-36%) were observed following shorter periods of remission (one to two years) and lower rates of recurrence (10-11%) following extended periods (8-10 years) of remission. Despite recurrence only being examined in two cohorts, these findings are low and clinically promising, suggesting that once a state of symptomatic remission is achieved, the likelihood of recurrence is low.

High drop-out rates of greater than 20% at follow-up may have led to the overestimation of the remission rate in three cohorts, resulting from being lost to follow-up, refusal to participate, suicide or death by natural causes (Gunderson et al., 2011; Links, Heslegrave & Van Reekum, 1998; Links et al., 1995; Paris & Zweig-Frank, 2001; Paris, Brown & Nowlis, 1987). Despite this, all studies engaged in a similar method of locating patients at follow-up (contacting patients via mail, phone or their therapists) and may favour individuals who are less engaged in vocation or have lower levels of functioning as they continued in treatment.

The variability in retainment rates appeared to be influenced by the range of follow-up years and where patients were recruited. Shorter follow-up periods were associated with a higher

diagnosis retainment rate, however this was not observed within the cohort from Gunderson and colleagues' study (2011). The low retainment rate (9%) following 10 years of follow-up identified is an interesting yet promising finding compared to the higher figures identified by other cohorts (Pope et al., 1983; Links et al., 1995, Links Heslegrave & Van Reekum, 1998). This however may be explained by the greater proportion of outpatients included in Gunderson and colleagues' (2011) study compared to other cohorts which have only included an inpatient sample (Pope et al., 1983; Links et al., 1995, Links Heslegrave & Van Reekum, 1998). Differences between individuals initially treated within an inpatient or outpatient setting have not been examined within longitudinal studies, although it may be assumed that individuals in outpatient settings are less symptomatic compared to those within inpatient settings. Recent treatment guidelines endorse the treatment of individuals with BPD best occurs within the community (National Institute for Health Care Excellence, 2009; National Health and Medical Research Council, 2012), thus further investigation is required.

3.6.2 Greater Understanding of Personal Recovery in BPD is Required

The strong focus in the literature on clinical remission, rather than personal recovery, is not a surprising finding, given the severity of the disorder and the significant impact BPD can have on quality of life. This coincides with the increasing number of psychotherapeutic interventions designed specifically for the treatment of BPD. A focus on improving clinical characteristics of BPD to facilitate change was identified within qualitative studies. Although only one study (Katsakou et al., 2012) identified specific treatments engaged in by participants, all qualitative studies included treatment seeking participants. Thus, themes reported in qualitative studies may be to a degree influenced by the theoretical orientation of treatments received. The alignment of treatment targets with personal recovery goals however, requires further investigation where discrepancies were identified in some studies.

Katsakou and colleagues (2012) identified that psychotherapeutic interventions did not address all treatment goals consumers had for recovery. Hence, it is suggested that the target goals of specific interventions designed for the treatment of BPD may not fully reflect the treatment goals of consumers. Developing insight into consumer goals and whether they are aligned to the goals predetermined by researchers will assist to understanding whether interventions need to be adapted to better accommodate consumers throughout treatment and assist in developing mental health services that are recovery-oriented. Findings of the current review suggest that functioning of consumers with BPD improve over an extended period of time. However, the average level of functioning indicates that consumers have ongoing difficulties with functioning, with approximately 65% of consumers not engaged in a vocation during the follow-up period. This is consistent with previous research examining vocational functioning in individuals with BPD (Skodol et al., 2002), however research has noted higher rates of psychosocial functioning is observed compared to vocational functioning (Zanarini et al., 2010; Skodol et al., 2002). Although low rates of vocational engagement were identified in the review, qualitative studies identified a strong desire from consumers for meaningful roles and employment, suggesting that despite intentions, symptomatic remission may not be sufficient to allow consumers engage in their desired level of vocation.

The desire for vocational engagement however, was not identified as the only facilitator of recovery where the completion of day to day activities contributed to a consumer's willingness to engage in the recovery process. This not only exemplifies the personalised nature of recovery journey but also indicates that the stage of recovery may influence a consumer's perceived ability to engage in vocation and activities. To strengthen the level of societal participation, recommendations for the integration of psychiatric rehabilitation as part of the treatment of BPD have been suggested in the literature (Skodol et al., 2002;

Weinberg, Ronningstam, Goldblatt, Schechter, & Maltsberger, 2011; Zanarini et al., 2010). However, little is known about the stages of recovery from BPD and whether differing recovery stages require adapted approaches to better suit the consumer. Greater consideration of the association between a consumer's self-rated stage of recovery and their narratives may provide insight into the needs of individuals at different stages of recovery and also how psychiatric rehabilitation services can incorporate this into care.

3.6.3 Consumer Conceptualisations of Recovery Requires Further Investigation

Findings from the qualitative studies indicate that the word 'recovery' may not fully encapsulate the experiences of consumers with BPD. Two papers included in the review (Lariviere et al., 2015; Katsakou et al., 2012) discuss the concerns of consumers; however do not propose a more holistic conceptualisation. This is a unique finding as previous research examining recovery in other mental illnesses has readily used the term to describe the consumer experience (Davidson, Lawless & Leary, 2005; Deegan, 1988).

The shift away from understanding recovery purely from a clinical perspective was highlighted in both longitudinal and qualitative studies, where symptom management and reduction was not identified as a consumer's highest priority. The engagement in vocation and activities was prioritised by consumers, further suggesting that clinically focused conceptualisations of recovery may not describe the recovery experience. This also reflects differences between the definition of clinical and personal recovery and indicates that these notions of recovery may be interconnected. This is consistent with suggestions that clinical and personal recovery is complementary of each other (Davidson, Lawless & Leary, 2005; Slade, 2009). Although a number of conceptual frameworks describing personal recovery

have been posited in the literature (see Andresen et al., 2003; Leamy et al., 2011 for review), limited research in the literature has examined how clinical recovery fits into the conceptual frameworks of recovery.

Conceptualising recovery in light of consumer views may be a more holistic approach to understanding outcomes in BPD. This can include shifting away from solely focusing upon the acute clinical symptoms by incorporating individualised assessments in determining outcomes. Gaining understanding of consumer goals for treatment and recovery and incorporating their views into clinical practice and psychotherapy research may assist to personalise interventions to suit individual consumers.

3.6.4 Perspectives of Family and Carers are Needed in the Literature

At present, no studies have examined the perspectives of family and carers on recovery. Considering the increased caring role family and carers have taken on since the deinstitutionalisation of mental health services overcoming this limitation is important, especially given the burden of caring reported in recent work (Bailey & Grenyer, 2014; Bailey, & Grenyer, 2013; Dunne & Rogers, 2013; Giffin, 2008). Differences between carers and consumers over the factors attributed to recovery have also emerged (Noiseux et al., 2010), however these perspectives have not been specifically applied to BPD and limited understanding into the actions or strategies adopted by family and carers to promote recovery in their loved ones on a day to day basis have been examined in the literature. Understanding the facilitators and hindrances associated with recovery through multiple perspectives may lead to the strengthening or adaptation of actions and strategies to facilitate recovery.

Similarly the perspectives of mental health clinicians on the recovery journey in BPD were also absent. Misunderstandings surrounding what constitutes as recovery has also been

identified as a barrier to clinicians promoting recovery (Rogers, & Dunne, 2013). Differences in understanding may have detrimental effects on therapeutic alliance. Gaining a clear understanding into how clinicians perceive recovery and whether these perceptions align to consumers' perspectives may assist with strengthening the therapeutic alliance.

3.6.5 Strengths and Limitations of the Review

Although only one researcher screened and assessed articles for review inclusion, the greater focus on the clinical aspects of recovery in BPD identified by the systematic search limits has the capacity to provide a balanced review of this area. The absence of studies meant a holistic view of the recovery process from the perspectives of consumers can only be gleaned from what is available. Despite similarities in the diagnostic criterion used (for example DIB, DSM-III, DSM-IV and Gunderson & Kolb's (1978) criteria), each criteria have different definitions for what is considered remission or relapse. Skewed results may result and these differences may have an impact upon understanding patient outcomes between studies.

The exclusion of the forensic settings from this study may have had the effect of reducing the opportunity to include males with BPD in this review, since it is known that such settings have a high proportion of males with BPD. The specific impact of incarceration or other forensic involvement on recovery from BPD is unknown. We recommend that future studies specifically study this group, in order to progress our understanding of recovery from those who have the disorder. Such work may also help to understand the effect on BPD recovery from varying rates and durations of incarceration or involvement in the criminal justice system.

The review excluded studies with a follow-up period of less than five years and all intervention related studies. This resulted in the exclusion of studies examining the

effectiveness of treatments, as these would provide a description of the treatment effects and mechanisms driving change rather than long-term outcomes. The types of treatments received by consumers however, may influence the factors associated with recovery identified from both the longitudinal and qualitative studies. Future research could identify whether a relationship between the types of psychotherapeutic interventions received with the types of treatment goals consumers have for recovery.

3.7 Conclusion

Despite increasing evidence that symptomatic remission from BPD is possible, the focus on traditional understandings of recovery has been questioned by consumers, where a more holistic approach has been called for. It may be that a better understanding of recovery includes maintaining sub-threshold symptom expression, engaging in vocational activities that are personally meaningful, and sustaining close personal relationships. Further research is needed to define personal definitions of recovery from BPD. This is in contrast to traditional notions of recovery (as absence of symptoms) and acknowledges that difficulties in functioning may persist, as noted by findings reviewed here. Additionally, the increasing role of a consumer's support network in contributing to their recovery has been acknowledged, however this has not translated into the research literature. Understanding of the views, perspectives and difficulties clinicians and family and carers may have towards recovery in BPD will assist in understanding interactions between these groups and to identify implications for comprehensive treatment.

CHAPTER FOUR

Phase Two

What do Individuals with Borderline Personality Disorder Want from Treatment? A Study of Self-Generated Treatment and Recovery Goals

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The permission to reproduce statement for the manuscript was sought and presented as Appendix A, with the full manuscript as Appendix M.

4.1 Preface

Based on the systematic review (Chapter Three), to date the clinical literature has received more attention, resulting in recommendations for greater understanding of the perspectives of individuals with lived experience. One finding from the systematic review pertained to the differences between treatment targets, and the goals of individuals seeking treatment. Whilst goals associated with personal development and interpersonal skills have been identified, these may not encapsulate all the goals individuals may have. Gaining an understanding of personally meaningful goals may lead to individuals having a more informed choice in care pathways.

Chapter Four describes a study which content analysed the self-generated treatment goals of 102 individuals seeking treatment at a community-based psychotherapy program. The Target Complaints Measure (Battle et al., 1966) was used as a guide during the first assessment session to collect goals from individuals.

4.2 Abstract

Outcome measurement has progressed in the personality disorder field. Whilst the majority of trials have understood outcomes through symptom and diagnostic indices, what is a considered meaningful and valued outcome to individuals has been seldom investigated. Self-generated treatment goals from 102 individuals seeking treatment for BPD were collected and independently coded by two raters. Responses were content-analysed to determine the categories of goals people want for treatment. A total of 464 individual goal units across four main goal types emerged in the content analysis: reducing symptoms, improved wellbeing, better interpersonal relationships, and having a greater sense of self. Although the reduction of symptoms was the most commonly reported goal, 88.2% reported wanting better psychosocial functioning, including improvements in relationships, vocation and self-understanding. The existence of the wide range of goals suggests that there is a need for clinicians to establish a collaborative formulation of treatment goals with individuals to ensure treatment is personalised and meaningful.

Keywords: Borderline Personality Disorder, Treatment Goals, Recovery, Qualitative, Personalised Treatment

4.3 Background

Examining outcomes in the personality disorder field has progressed since the first published randomised control trial (RCT) in 1991 (Linehan, Armstrong, Suarez, Allmon, & Heard, 1991). In a recent systematic review, 33 RCTs were identified to evaluate the efficacy of interventions for people with borderline personality disorder (BPD) (Cristea et al., 2017). Specialist interventions for BPD have treatment goals which target changes in behaviour, such as in Dialectical Behavioural Therapy (Linehan et al., 1991) or the specific modification of representations and understanding of self and other, for example in Schema Therapy, Transference Focused Psychotherapy and Mentalisation Based Treatment (Bateman & Fonagy, 2010; Kellogg & Young, 2006; Kernberg, Yeomans, Clarkin, & Levy, 2008). However, measures used in intervention trials usually measure only the key symptoms and service use. Consumer reports suggest that we need to go beyond symptom change (Katsakou et al., 2012) and measure a broader set of recovery goals. This has been supported by the literature which has reported a disconnect between service targets and personal goals of individuals with BPD (Katsakou et al., 2012) and the recognition that recovery extends beyond symptom remission (Ng, Bourke, & Grenyer, 2016).

Given the international shift towards recovery-oriented mental health servicing and the provision of person-centred care (Le Boutillier et al., 2011), questions remain over what individuals perceive to be important to them at the start of treatment. Various attempts to personalise treatment and focus on service user generated goals in other diagnoses have been made. The Camberwell Assessment of Need (CAN) (Phelan et al., 1995) is one example and measures the met and unmet needs of individuals across 22 health and social domains. The aims of the CAN diverge from conventional clinical assessment, as it differentiates between the met needs, met through the provision of services and unmet needs which are identified

areas requiring further intervention or support. Limited research has been conducted into what individuals with BPD value. In a study examining the met and unmet needs of people with personality disorder, eight key areas of unmet need were identified, 'self-care, psychotic symptoms, psychological distress, risk to self, risk to others, alcohol use, sexual expression and budgeting' (Hayward, Slade, & Moran, 2006, p541). Whilst the majority of these unmet needs are reflective of the symptomatic difficulties known to be experienced by individuals with personality disorder, this also provides an indication of the domains which require greater investigation.

One approach to personalising treatment and focusing on the goals generated by service users has been through understanding the target complaints of individuals at the start of therapy. Measures such as Battle's Target Complaints Measure (Battle et al., 1966) provide an opportunity for individuals to spontaneously formulate and identify their own goals to guide the direction of therapy. The impact of personalised treatment goals have been identified to produce larger effect sizes than symptom checklists when evaluating the effectiveness of psychotherapy in clinical trials (Lindhiem, Bennett, Orimoto, & Kolko, 2016). The identification of specific goal categories individuals value may be important in understanding treatment needs and develop new ways of personalising treatment. This study aims to examine the personally meaningful treatment goals of individuals seeking treatment for BPD.

4.4 Method

4.4.1 Study Design and Participants

This qualitative study utilised data collected from individuals who were seeking treatment for BPD at a community-based psychotherapy program. Individuals were assessed for suitability for the program and were only admitted if they were aged over 18 years and had a primary

diagnosis of DSM-IV BPD, diagnosed using the Structured Clinical Interview for DSM (SCID-I and SCID-II) (First, Gibbon, Spitzer, Williams, & Benjamin, 1997; First, Spitzer, Gibbon, & Williams, 1997), by two trained doctoral level clinical psychologists. Individuals were excluded from the program if there was indication of substance abuse, or they met criteria for a primary diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder with psychotic features or a history of neurological disorder. All participants were fluent in English and gave explicit informed written consent (including consent for the audio-recording of clinical assessments) following approval from the institutional review board.

4.4.2 Procedure

Participants were entering a year-long program of treatment. Individual goals for treatment were self-generated by participants at the first assessment session and was guided using the Target Complaints Measure (Battle et al., 1966). Goals were able to be both specific and more general and long-term in focus and were not delimited by clinicians in any way. The Target Complaints Measure is a semi-structured clinician guided interview, which was used as part of the intake assessment session to ascertain each participant's treatment goals or chief complaints (Battle et al., 1966). Participants were asked 'I want you to tell me in your own words the most important problems that you have that you want help with to change by coming here. These are the kind of goals you might have for your treatment' as specified by the Target Complaints Measure (Battle et al., 1966). Participants were prompted to provide up to three goals and to self-rate how severe these were an issue or problem for them on a scale of 0 (not a problem/least severe issue for me) to 10 (the worst/most severe issue for me).

4.4.3 Data Analysis

An inductive conventional content analytic approach to understanding the goals of individuals and the development of goal categories was used. This followed a three-step approach as described by Hsieh and Shannon (2005).

Participant description of goals were audio-recorded and transcribed verbatim. Researchers immersed themselves in the data by reading and reflecting on participant responses to gain an overall understanding. Firstly, participant responses were tagged with codes, referred to as goal units, to accurately describe the data. Due to the recognition that multiple goals could be present within an individual goal, some goals could be represented by more than one code. Thus, although the Target Complaints Measure (Battle et al., 1966) specified up to three goals, some participants provided more than three goals within their descriptions. Secondly, similar or related codes were condensed into goal categories that allowed for both homogeneity within the group and heterogeneity between groups. Lastly, goal categories were grouped into meaningful themes to represent participant responses. The coding process was supported by the use of the NVivo 10 software for qualitative data analysis. The data was initially independently coded and categorised by two researchers, this was followed by the discussion and review of codes by a third researcher who is an expert in personality disorders. The trustworthiness of the data was ensured by having consistent discussion about codes and findings emerging from the data with the wider research team to ensure that concepts were not overlooked within the data. Through multiple discussions and reviews, the coding and categorisation of codes were refined. Discrepancies amongst the coding and the subsequent categories between researchers were discussed and resolved through consensus. Illustrative quotes of the goals were provided to support and provide evidence for the interpretations of

the researchers. Researchers analysing the data were independent from clinicians providing psychological care to participants.

4.5 Results

4.5.1 Characteristics of Participants

A total of 102 consecutively recruited participants seeking treatment meeting a primary DSM-IV-TR diagnosis of BPD were invited to participate. All gave written informed consent to the study. Table 6 outlines the demographic characteristics of participants.

Table 6. Characteristics of participants

Characteristic	Range	n (%) or Mean (SD)
Female		89 (87.3%)
Age	18 – 56 years	29.7 years (8.84)
Relationship Status:		
Single		57 (55.9%)
Married		20 (19.6%)
De-facto		11 (10.8%)
Divorced		7 (6.9%)
Separated		7 (6.9%)
Years of Education	7.5 – 19 years	12.1 years (2.58)

4.5.2 Treatment Goals Identified by Participants

Overall, participants identified a total of 268 goals, with an average of 2.8 goals per participant. All participants (100%) were able to report one goal, 100 participants (98%) reported two goals, and 86 participants (84%) were able to report three goals. The majority of goals identified had multiple components. The goals reported were then analysed into

constituent units, making a total of 464 individual goal units (See Table 7) or 4.5 goal units per participant. Reported goals could include the same individual goal unit on multiple occasions in their descriptions, this however was only counted once. Therefore, goal units identified in Table 7 are indicative of the number of participants endorsing a specific goal unit.

Findings from the content analysis reveal four key themes associated with treatment and personally meaningful goals for recovery. The reduction of symptoms was the most commonly reported goal by participants (n=88, 86.3%), followed by the desire to improve wellbeing (n=64, 62.7%), having better interpersonal relationships (n=54, 52.9%) and having a greater sense of self (n=40, 39.2%). Although reducing symptoms was the most commonly reported theme, 90 participants (88.2%) also reported at least one goal pertaining to a psychosocial goal category. Goals identified by participants were identified to not be mutually exclusive, such that achievement of goals in one area contribute to improvements in other areas.

Table 7. Formulated themes and frequencies of participant-generated goals verbalised at the commencement of treatment for Borderline Personality Disorder (N=102, 464 individual goal units)

Formulated theme and goal categories	**Participant-generated goal statements**	**Number of participants endorsing the theme (% of all participants)**
Goal Theme: Reducing Symptoms (5 goal categories, 17 goal units)		**88 participants (86.3%)**
Suicidality and Impulsivity (51 participants, 50.0%)	Self-harm behaviours/thoughts	22 (21.6%)
	Suicidality	17 (16.7%)
	Anger	15 (14.7%)
	Drug and alcohol misuse	7 (6.9%)
	Gambling urges	2 (2.0%)
	Shoplifting	2 (2.0%)
Depressive Symptoms (42 participants, 41.2%)	Negative mood/thoughts	36 (35.3%)
	Mood swings	6 (5.9%)
Anxiety Symptoms (40 participants, 39.2%)	General anxiety	17 (16.7%)
	Post-traumatic stress/trauma	17 (16.7%)
	Panic attacks	7 (6.9%)
	Social anxiety	5 (4.9%)
	Specific phobia	5 (4.9%)
Eating Related Issues (11 participants, 10.8%)	Disordered eating	7 (6.9%)
	Weight loss	4 (3.9%)
Transient Symptoms (8 participants, 7.8%)	Dissociation	6 (5.9%)
	Hallucinations	2 (2.0%)
Goal Theme: Improving Wellbeing (4 goal categories, 14 goal units)		**64 participants (62.7%)**
Coping Style (46 participants, 45.1%)	Having control over emotions	25 (24.5%)
	Improve coping style	17 (16.7%)
	Coping with distress/stress	15 (14.7%)
	Having control over thoughts	7 (6.9%)
	Improve functioning and use of skills	8 (7.8%)
	General sense of control	2 (2.0%)
Vocation (21 participants, 20.6%)	Engaging in paid work	9 (8.8%)
	Engaging in activities	8 (7.8%)
	Education	5 (4.9%)
Current Life Situations	Solve specific life situations	14 (13.7%)

(18 participants, 17.6%)	Financial situation	4 (3.9%)
Physical Health	Improve physical health	5 (4.9%)
(9 participants, 8.8%)	Stay out of hospital	3 (2.9%)
	Come off medication	1 (1%)
Goal Theme: Better Interpersonal Relationships (4 goal categories, 14 goal units)		**54 participants (52.9%)**
Interpersonal skills	Overcome my grief and loneliness	10 (9.8%)
(23 participants, 22.5%)	Being assertive with others	5 (4.9%)
	Trusting others	4 (3.9%)
	Become independent	3 (2.9%)
	Reduce abandonment fears	2 (2.0%)
Improving Current Relationships	Relationship with my significant other	6 (5.9%)
(22 participants, 21.6%)	Relationship with my friends	6 (5.9%)
	Relationship with my family	6 (5.9%)
	Relationship with my mother	5 (4.9%)
Connectedness	Connecting with others	12 (11.8%)
(21 participants, 20.6%)	Developing relationships	7 (6.9%)
	Relating to others	5 (4.9%)
Parenting	Develop my parenting skills	6 (5.9%)
(8 participants, 7.8%)	Have contact and a better relationship with my children	4 (3.9%)
Goal Theme: Greater sense of self (2 goal categories, 11 goal units)		**40 participants (39.2%)**
Attitudes Towards Self	Having self-esteem and self-worth	12 (11.8%)
(27 participants, 26.5%)	Sense of self	9 (8.8%)
	Having self-confidence	4 (3.9%)
	Become self-accepting	3 (2.9%)
	Improve self-image and reduce perfectionism	3 (2.9%)
Personal Awareness	Understanding myself	10 (9.8%)
(23 participants, 22.5%)	Develop my goals and motivation	8 (7.8%)
	Identifying my vulnerabilities	5 (4.9%)
	Reducing feelings of emptiness	4 (3.9%)
	Having a sense of purpose	2 (2.0%)
	Having my own opinions	2 (2.0%)

4.5.2.1 Reducing Symptoms

The goal of reducing symptoms was the most commonly cited theme in the study, where reducing suicidality and impulsivity, anxiety symptoms, and depressive symptoms were some of the most highly reported goal categories. Participants discussed the impact of symptoms upon daily functioning and self-perceptions. *"I'd certainly like to manage my depression better, so that I don't end up back in hospital again. I'd like to be able to explore things that may be affecting me as an adult so that I can understand why I feel the way about things that don't make sense. I just want to get on with my life, be a whole person rather than be in fragments."* (Individual 5091)

The experience of symptoms were sometimes inter-related such that the experience of depressive or anxiety symptoms corresponded with desire to engage in self-harming behaviours or increased suicidality. The reduction of symptoms had a compounding effect on a person's ability to engage in and achieve other psychosocial goals. *"I want to be able to deal with the depression and cope with distress… I'd like to get to a point where I can go back to do some study or do some work."* (Individual 3054)

4.5.2.2 Improving Wellbeing

Goals pertaining to improving wellbeing were global in nature and individual differences contributed to the heterogeneity of the goals. The desire to improve coping style was one of the most highly reported goal categories by participants and widely reflected the overall desire to improve symptomatically. The ability to effectively manage emotions and thoughts contributed to improved quality of life and emotional experience. *"To learn how to control the fuzziness that leads to those instances and slowly reducing the want, need and the action of self-harm"* (Individual 5086). Goals associated with improving current life situations and

financial situation were also at times interconnected with symptoms and interpersonal relationships. Life situations mentioned were broad and included court cases, assault, divorce and the loss of a child. *"At the moment, the involvement of court case for sexual assault is very stressful… It has restricted parts of my life, through avoiding people and avoiding relationships. Want to get on with life and put it behind me"* (Individual 3051). Despite goals to improve life situations, one participant articulated that these may be considered *"general life problems"* (Individual 5076), highlighting the common experiences of individuals.

Vocational pursuits such as engagement in paid work and education were valued goals. Despite the desire to be connected with society, the emotional intensity experienced by participants was identified as a barrier. *"Being employable, but when you look at my CV, it's like what have you been doing all these years? Getting a part time job is really important. If I took on a full time position I would let down my employer and myself because it has been a few years since I have been in work"* (Individual 5100). Yet, it was recognised that participation in structured vocation may not be suitable for all individuals, such that assisting individuals to take part in personally meaningful activities would be a valued target of treatment. *"I really want to do dancing. Dancing used to really help me… I think it is teaching myself to go there and not matter whether I will be put down for it."* (Individual 5151)

4.5.2.3 Better Interpersonal Relationships

Better interpersonal relationships were another key theme associated with developing a sense of connectedness with others, improving current relationships, and developing interpersonal skills. Connectedness was described by participants to be on a continuum from developing relationships, connecting with others, and relating to others. *'Just being able to feel like I fit*

somewhere, I feel like I don't fit. I'm too scared to go out and meet new people… It is a big problem cause I don't do anything.' (Individual 5106)

The difficulty relating with others was acknowledged and could be improved through a process of developing greater communication, engagement and understanding of others. The development and improvement of interpersonal skills reported reflected the need to overcome grief and loneliness, to be more assertive, and establishing trust with others in order to more effectively initiate or engage in relationships. *"Be able to go with my own judgement or my own decision, instead of running to my father all the time and his opinion – like decision making and assertiveness. I don't trust my own judgement and I am not very assertive either"* (Individual 5078). Relationships were mainly discussed by participants in the context of their significant others, friends, family, and their mother. Specific goals to improve parenting capacity were also identified by participants.

4.5.2.4 Greater Sense of Self

The theme of developing a greater sense of self was associated with improving attitudes towards self and increasing personal awareness. Personal awareness was achieved through developing greater self-understanding and being able to conceive of what might be a meaningful life direction or goal, and have motivation to move in that direction. *'Be more of a whole person…learning some tools that will help me be motivated to get out and do things and enjoy life instead of dragging myself through it, all the time.'* (Individual 5091)

Some participants broadly discussed goals to 'get to know who I am' whilst others discussed a desire to shift away from a 'victim persona' developed from experiences of trauma and to no longer be viewed only through the lens of their BPD diagnosis. '*I have childhood issues and I'm hanging onto them. I'm dealing with them really well… but still need help to deal*

with some of those issues, how to not be a victim' (Individual 3054). Goals pertaining to the development of self-esteem and self-worth were discussed, as were the negative consequences of poor self-esteem and self-worth *'If I consciously self-harm it is because of my self-esteem. I just hate myself'* (Individual 5090).

There was recognition from some participants that improving self-esteem may be an ongoing journey, however a person's attitude towards themselves was inextricably linked with increasing personal awareness. The ability to separate oneself from others in order to develop a sense of who they are and a sense of genuineness was also identified by some participants. *"Getting to know me… I want to be more consistent. I've gotten to the point where I push people away because I can't be me and I am sort of resenting them for it, even if they are not doing it"* (Individual 5113).

4.6 Discussion

This study explored the views of individuals seeking treatment for BPD on their personally meaningful goals for treatment. Participants identified four main goal categories; reducing symptoms, improving wellbeing, better interpersonal relationships and having a greater sense of self. Personally meaningful treatment goals identified in this study extend beyond the reduction of symptoms to include those of a psychosocial nature, supporting the calls to expand the outcome measures to include aspects which are global in nature such as subjective wellbeing and the views of individuals seeking treatment (Howard, Lueger, Maling, & Martinovich, 1993; Thornicroft & Tansella, 2005). The goal themes identified were consistent with research examining the lived experience of individuals with personality disorder (Gillard, 2015; Katsakou et al., 2012; Shepherd et al., 2017) and reflected some of the domains present in the Camberwell Assessment of Need (Phelan et al., 1995). Domains of psychopathology in BPD were also reflected in identified goals (Sanislow et al., 2002),

including difficulties in relational functioning, emotion dysregulation, and understanding self and others. However, the identified goal themes and categories extend upon the work to date in the literature by providing greater insights into the specific aspects which may be important to individuals that could be potentially targeted during treatment.

The identification of symptom reduction as the most cited theme was not surprising given the severe nature of BPD and that individuals were at the start of treatment. Interestingly, studies of lived experience of personality disorder view have conceptualised recovery as the reconciliation of self and other representations through the development of a sense of self which could be achieved through the engagement of interpersonal relationships and the community (Katsakou et al., 2012; Turner, Lovell, & Brooker, 2011). Although these themes are reflected in the current study's findings, less than half the participants reported goals associated with developing a greater sense of self. This may be associated with the sample being at the start of treatment, which contrasts to other studies where participants were engaging in a specialist intervention and therefore were more aware of their underlying difficulties. This may also be reflective of the shifting nature of treatment goals and suggestive that routine monitoring of goals may be required.

Treatment goals reported were not mutually exclusive, such that participants believed that improvements in one goal would contribute to the achievement of other goals. This suggests that there may be multiple processes and challenges involved in achieving desired recovery outcomes in a personally meaningful manner. Although the identification of these processes and challenges were beyond the scope of this study, understanding these will have further implications for clinical practice and can provide guidance for the development of recovery-oriented mental health services for BPD.

4.6.1 Implications for Clinical Practice

The narrow treatment targets of interventions for BPD have been reported as a limitation to care by individuals with BPD (Katsakou et al., 2012). Although this study identified similarities between individual treatment goals and the typical targets of interventions, some identified goal categories and units did reflect that a wider focus may not be captured in psychotherapeutic interventions and treatment manuals for BPD. There is room from the findings reported here for treatment manuals to focus more broadly on goals identified by individuals. Having broader treatment targets may also have the effect of generating greater motivation for behavioural change and improving treatment engagement. Additionally, the therapeutic alliance between clinicians and individuals could also profit from the greater awareness of individual goals.

The development of new methods of integrating existing psychotherapeutic evidence-based approaches with psychosocial interventions may be important in assisting individuals with BPD achieve their desired outcomes (Frese, Stanley, Kress, & Vogel-Scibilia, 2001). The findings from this study provide a basis for understanding areas of importance to individuals with BPD. Evidence-based social interventions and psychosocial rehabilitation interventions such as illness management and recovery (Mueser et al., 2002), assertive community treatment (Stein & Test, 1980) or individual placement and support (Burns et al., 2007) may assist to support individuals with BPD in achieving goals which extend beyond the scope of the current manualised interventions with an evidence base. Additionally, developing the capacity of individuals with lived experience to become peer support workers may also present a unique opportunity for individuals with similar experiences to learn from each other (Repper & Carter, 2011).

The development of enhanced therapeutic interventions which target specific goals of interest to individuals with BPD may also be relevant. One recent example of such an intervention pertains to improving the parenting capacity of individuals with BPD who are also parents (McCarthy, Lewis, Bourke, & Grenyer, 2016). Continual evaluation of the integration of these interventions to evidence-based interventions should be completed using multiple measures and methodologies.

4.6.2 Limitations and Future Research

Treatment goals reported by participants in the current study were framed in a clinically-oriented manner, such that goals predominately focused upon the symptoms and problems participants wanted to overcome. Although this can be attributed to the context in which goals were formulated, they may also be reflective of individuals who are at the start of their recovery journey. The goals, however, provide a good indicator of the valued outcomes through the perspectives of individuals seeking treatment. The wide range of individual goal units (N=464) identified is also indicative of the personal nature of treatment goals and the need for mental health clinicians to ask individuals what their goals are for treatment, particularly given the links between goal consensus, collaboration and attainment (Clarke, Oades, Crowe, Caputi, & Deane, 2009; Tryon & Winograd, 2011). Goals for treatment and recovery are not static. This is reflected in the non-linear trajectory of recovery (Slade, 2009). More research examining changes in goal content longitudinally may provide a more nuanced understanding of the differences between individuals who may be at different stages of their recovery and whether treatments received are assisting individuals to attain their goals.

CHAPTER FIVE

Phase Three

The Role of Self-Identified Recovery and Diagnostic Status on Outcomes in Borderline Personality Disorder: A Mixed-Methods Study

This chapter has been submitted for review in *Social Psychiatry and Psychiatric Epidemiology* as:

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Additional illustrative quotes to demonstrate the definition of recovery as described by individuals are presented as Appendix N. This is presented to provide additional supporting evidence of the themes identified in the qualitative analysis.

5.1 Preface

The systematic review (Chapter Three) identified that clinical recovery is possible and that the likelihood of relapse following a period of remission is low. The perspectives of individuals with lived experience were, however minimally explored. Chapter Four builds on this knowledge through findings that the treatment goals of individuals extend beyond symptom reduction to include improved wellbeing, improved interpersonal relationships, and a greater sense of self. The high proportion of individuals reporting at least one psychosocial goal suggests that the manner in which individuals define and describe recovery may differ to what is conceptualised within the clinical literature. This also suggests that there may be an association between clinical and personal recovery constructs in BPD.

Chapter Five reported on a study that empirically explored the role of an individual's self-identified recovery status and diagnostic status on clinical and personal recovery outcomes in 349 individuals with a diagnosis of BPD.

5.2 Abstract

Purpose: Personal recovery has been identified as an individual process, where the individual is the expert of their own experience. Whilst the majority of research focuses on clinical outcomes, an individual's perception of their own recovery may also influence outcomes. This study aimed to explore outcome differences in individuals with a diagnosis of borderline personality disorder (BPD) based on three different criteria - diagnostic status, self-identified recovery status, and combined diagnostic and self-identified recovery status.

Methods: This mixed-methods study consisted of survey responses from 349 individuals with a self-reported diagnosis of BPD. Measures of BPD symptomatology and self-identified recovery status was used to understand differences in personal and clinical recovery outcomes. Personal definitions of recovery in BPD were thematically analysed to understand what constitutes recovery in BPD.

Results: Individuals predominately met criteria for BPD (90%) or self-identified with being not recovered (79.1%). There was concordance between diagnostic and recovery status in 75.4% of individuals with less individuals who did not meet criteria and self-identified with recovered (3.2%). Diagnostic status was predicted by age, relationship status and score on MHI-5, yet no variables were predictive of self-identified recovery status. Self-identified recovery status had a significant main effect on personal and clinical recovery outcomes, whilst diagnostic status had an effect on clinical recovery only. Individual definitions indicated recovery could take on two definitions, recovery as self-management or recovery as not possible.

Conclusion: An individual's self-identified recovery status may be an important consideration understanding outcomes in BPD.

5.3 Introduction

The concept of recovery in mental health continues to evolve, with a growing appreciation of clinical and personal notions of recovery. Clinical recovery have attracted in-depth empirical evaluation, where emphasis is placed on symptom amelioration and return to previous levels of function (Bellack, 2006; Roe et al., 2011). Longitudinal studies in BPD have demonstrated the upward trend towards symptom remission. Despite differences in measurement, remission occurs in 33-99% and relapse in 10-36% of individuals, following 4-27 years of follow-up (Ng et al., 2016). Therefore, remission in BPD is common and the likelihood of relapse following a period of remission is low. Difficulties with functioning continue to persist despite the remission of symptoms (Ng et al., 2016).

Advances in the field have seen the introduction of newer categorisations of outcomes in longstanding longitudinal studies. For example, the McLean Study of Adult Development examined the concept of 'good recovery', operationalised as no longer meeting the diagnostic criteria for BPD for two years, and having a Global Assessment of Functioning (GAF; American Psychiatric Association [APA], 2000) score greater than 61 (Zanarini, Frankenburg, Reich, & Fitzmaurice, 2010; Zanarini, Temes, Frankenburg, Bradford Reich, & Fitzmaurice, 2018). Individuals would be characterised as having mild symptoms or some difficulties in functioning but, would be considered as functioning well and having meaningful relationships (APA 2000). Recent follow-up waves have seen the introduction of the concept of 'excellent recovery', referring to individuals who meet the symptom remission criteria and have a GAF score of greater than 71 (Zanarini et al., 2018). Significantly less individuals (39%) achieve excellent recovery compared to the 60% of individuals achieving 'good recovery' (Zanarini et al., 2018).

Whilst these are important outcomes to consider, these measures are often objectively rated by clinicians. Recovery goals, identified through the perspectives of people with lived experience, indicates that there are overlaps with the domains of the GAF, such that the role of symptom management, relationships, and vocational involvement are emphasised (Ng, Carter, Bourke & Grenyer, 2019). These domains are reflected and extended upon in studies examining the recovery experiences of individuals with BPD (Katsakou et al., 2012; Ng et al., 2019; Shepherd et al., 2017). Additional domains, including the engagement in personally meaningful activities, empowerment, and hope have also been identified (Katsakou et al., 2012; Ng et al., 2019; Shepherd et al., 2017).

Personal recovery is defined as 'a deeply, personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness' (Anthony, 1993, p527). This broad definition highlights the personalised nature of recovery in mental health, such that the definition of recovery may differ between individuals and is best evaluated by the individual (Slade & Longden, 2015).

Empirical evaluation of clinical and personal recovery has derived predominately from correlational studies with individuals with severe mental health concerns (Bellack, 2006; Resnick et al., 2004; Roe et al., 2011; Tse et al., 2014). Common variables of interest included measures of personal recovery (incorporating elements such as hope, goals, and empowerment), life satisfaction, quality of life, knowledge and social support (Resnick et al., 2004; Roe et al., 2011; Tse et al., 2014). Whilst personal and clinical recovery have been identified to be related yet distinct constructs (Roe et al., 2011; Tse et al., 2014), the applicability of these findings to individuals with BPD requires further exploration. One study examining the differences of using an objectively rated definition of functioning

through the GAF compared to a measure of self-rated life satisfaction in a sample of individuals with BPD after 12 – 18 years of diagnosis revealed that the use of life satisfaction may be a better indicator of recovery (Zeitler et al., 2018).

The current study aimed to firstly, understand how individuals with BPD define recovery and secondly, explore the role of an individual's self-perceived recovery status (whether a person perceives themselves as recovered) and diagnostic status (whether a person meets diagnostic criteria) on clinical and personal recovery outcomes. Based on prior research, it was predicted that diagnostic status would better predict clinical recovery outcomes, whilst self-perceived recovery status would have an effect on both clinical and personal recovery outcomes.

5.4 Method

5.4.1 Participants

Participants were recruited from online sources such as social media and mental health organisations internationally. This method of recruitment has used previously in examining experience in personality disorder (Bailey & Grenyer, 2014). Individuals were invited to participate in the study if the met the following criteria: 1) self-reported a diagnosis of BPD provided by a mental health professional, 2) over 18 years of age, 3) able to consent to take part in study, and 4) ability to complete the survey in English. The study was approved by an institutional review board and all individuals provided informed consent to take part in the study.

A total of 588 individuals initially took part in the survey. Following the application of inclusion and exclusion criteria, 239 individuals were excluded from the analysis due to; not providing consent (n=7), not having previously received a diagnosis of BPD (n=70),

providing non-serious responses (n=8), not providing responses to the mandatory questions (n=150), submitting duplicate surveys as identified by IP address (n=3), and not meeting the age requirement (n=1). Mandatory questions were defined as providing responses to questions pertaining to an individual's self-identified recovery status and diagnostic status. The final sample included 349 individuals with a self-reported diagnosis of BPD (see Figure 2).

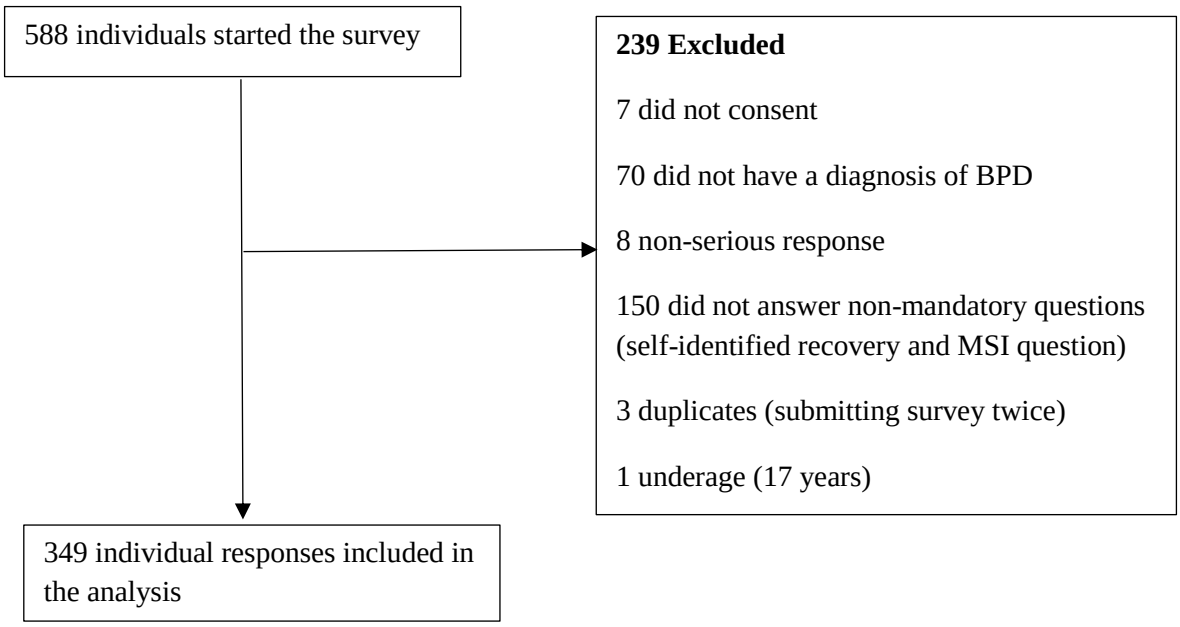

Figure 2. Flow chart of inclusion into the study

The majority of the sample were female (87.7%), aged between 18-65 years (M=33.43, SD=10.88). Overall, 73 individuals (20.9%), self-identified with being recovered, whilst the remaining 276 individuals, self-identified with being not recovered. The majority of the sample met criteria for BPD through the MSI (n=214, 90%), and on average participants endorsed 8.71 (SD=1.91) criteria. See Table 8 for demographic characteristics of participants.

Table 8. Differences in participant characteristics as a function of diagnostic status and self-identified recovery status

			Self-Identified Recovered (n=73)					Self-Identified Not Recovered (n=276)			
Variable	Statistic	Range	Total (N=349)	Total (n=73)	Meets criteria for BPD (n=62)	Does not meet criteria for BPD (n=11)	t (p) χ^2 (p)	Total (n=276)	Meets criteria for BPD (n=252)	Does not meet criteria for BPD (n=24)	t (p) χ^2 (p)
Age	M (SD)	18-65	33.43 (10.876)	35.37 (10.118)	34.95 (9.893)	37.64 (11.491)	-0.807 (0.423)	32.91 (11.032)	32.54 (10.878)	36.95 (12.116)	-1.804 (0.072)
Gender											
Female	% (n)		87.7% (n=306)	94.5% (n=69)	93.5% (n=58)	100% (n=11)	0.189 (0.664)	85.9% (n=237)	86.1% (n=217)	83.3% (n=20)	0.236 (0.627)
Years of Education (years)	M (SD)	0-16	14.279 (2.166)	14.586 (2.540)	14.627 (2.612)	14.364 (2.203)	0.314 (0.755)	14.194 (2.049)	14.165 (1.872)	14.50 (3.447)	-0.733 (0.464)
Length of Treatment	M (SD)	0-50	7.91 (7.832)	8.41 (7.139)	8.30 (7.183)	9.05 (7.192)	-0.317 (0.752)	7.78 (8.012)	7.57 (7.882)	9.98 (9.159)	-1.409 (0.160)
Relationship Status											
In a relationship	% (n)		48.7% (n=170)	52.1% (n=38)	40.3% (n=40.3)	63.6% (n=7)	1.689 (0.194)	47.8% (n=132)	49.6% (n=125)	29.2% (n=7)	3.453 (0.063)
Employment Status											
Engaged in paid work	% (n)		45.8% (n=160)	75.3% (n=55)	79% (n=49)	54.5% (n=6)	4.474 (0.034)*	38% (n=105)	38.1% (n=96)	37.5% (n=9)	0.001 (0.971)
Work hours per week	M (SD)	0-70	15.808 (17.417)	25.203 (16.665)	26.259 (16.553)	19.636 (16.913)	1.213 (0.230)	13.235 (16.751)	13.274 (16.913)	12.788 (15.124)	0.124 (0.901)
Age of onset	M (SD)	0-50	15.49 (7.418)	15.26 (7.710)	15.92 (8.073)	11.64 (3.722)	1.719 (0.090)	15.54 (7.352)	15.37 (7.295)	17.48 (7.856)	-1.320 (0.188)
Age of diagnosis	M (SD)	10-63	27.12 (9.632)	28.04 (9.204)	28.15 (8.963)	27.45 (10.912)	0.228 (0.820)	26.88 (9.744)	26.59 (9.660)	30.00 (10.313)	-1.612 (0.108)
Number of MSI items met	M (SD)	0 – 10	8.71 (1.907)	8.151 (2.498)	9.048 (1.108)	3.091 (2.071)	9.305 (0.000)**	8.862 (1.691)	4.583 (1.742)	9.270 (0.969)	12.986 (0.000)**
Personal Recovery											
RAS-DS Total	M (SD)	0-100	62.580 (13.816)	76.394 (12.036)	76.127 (11.326)	77.903 (16.049)	-0.449 (0.655)	58.831 (11.741)	58.015 (11.178)	67.558 (14.175)	-3.821 (0.000)**
RAS-DS Things I Value			67.093 (15.399)	77.283 (14.634)	77.621 (15.131)	75.379 (11.852)	0.466 (0.643)	64.328 (14.430)	63.652 (13.717)	71.558 (19.529)	-1.898 (0.070)
RAS-DS Looking Forward			60.454 (15.712)	75.506 (13.761)	75.040 (13.235)	78.131 (16.912)	-0.684 (0.496)	56.369 (14.554)	55.533 (13.04)	65.314 (16.274)	-3.363 (0.001)**
RAS-DS Mastering Illness			59.033 (17.135)	77.446 (12.845)	76.901 (11.760)	80.520 (18.236)	-0.859 (0.393)	64.658 (15.335)	53.209 (14.037)	62.888 (17.220)	-3.099 (0.002)**
RAS-DS Connecting and Belonging			67.220 (16.202)	76.663 (15.906)	76.613 (15.272)	77.903 (16.049)	-0.064 (0.949)	64.658 (15.335)	63.821 (14.983)	73.603 (16.533)	-2.968 (0.003) **
Quality of Life			46.795 (23.424)	65.729 (20.063)	65.322 (18.766)	67.909 (26.994)	-0.390 (0.698)	41.831 (21.670)	40.734 (21.377)	53.478 (21.805)	-2.729 (0.007)**
Clinical Recovery											
MHI-5	M (SD)	5-30	20.376 (5.015)	15.740 (4.455)	15.887 (4.278)	14.909 (5.522)	0.668 (0.506)	21.615 (4.397)	22.052 (4.052)	17.083 (5.299)	5.572 (0.000)**
Number of Disability Days		0-14	4.030 (4.128)	1.480 (2.411)	1.66 (2.538)	0.55 (1.293)	1.410 (0.163)	4.70 (4.226)	4.92 (4.204)	2.36 (3.812)	2.746 (0.006)**

Note: ** significant at the 0.01 level, * significant at the 0.05 level

5.4.2 Measures

5.4.2.1 Self-Identified Recovery Status

To ascertain an individual's self-identified recovery status, individuals were asked 'how do you define recovery from borderline personality disorder?' This provided individuals the opportunity to reflect upon and articulate their own definition of recovery in an open response format. Individuals were then asked, 'according to your own definition, do you consider yourself as recovered?' Individuals provided a 'yes' or 'no' response.

5.4.2.2 Diagnostic Status: McLean Screening Instrument for Borderline Personality Disorder (MSI-BPD)

Although all participants had a previous diagnosis of BPD provided by a mental health clinician, current diagnostic status at the time of interview was estimated through the MSI-BPD (Zanarini et al., 2003a), a 10 item self-report instrument used to screen for BPD. The measure was based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; APA, 2000), where a score of seven or greater indicates the presence of BPD. The MSI-BPD has good psychometric properties with high sensitivity (0.81), specificity (0.85) and reliability (alpha=0.74) (Zanarini et al., 2003a). Cronbach's alpha in the current sample was 0.80. This measure is used as a categorical and continuous measure in this study.

5.4.2.3 Personal Recovery

5.4.2.3.1 Recovery Assessment Scale - Domains and Stages (RAS-DS)

The RAS-DS (Hancock, Scanlan, Bundy, & Honey, 2016) is a 38 item self-report tool, which measures personal recovery. The scale is comprised of four domains; 1) Things I Value, 2)

Looking Forward, 3) Mastering Illness, and 4) Connecting and Belonging. Responses are indicated on a four-point Likert scale ranging from 'untrue' to 'completely true'. Whilst there is no specific cut-off for what is considered as 'recovered', higher scores indicate greater levels of recovery. The RAS-DS has good psychometric properties with high internal reliability, validity (alpha=0.96) and is sensitive to change over time (Hancock et al., 2016).

5.4.2.3.2 World Health Organisation Quality of Life (WHOQOL-BREF)

The WHOQOL-BREF is a self-report measure of subjective quality of life (The WHOQOL Group, 1998) and has demonstrated good psychometric properties in adult psychiatric outpatients (Trompenaars, Masthoff, Ven Heck, Hodiamont, & De Vries, 2005). One global item from the WHOQOL-BREF was used in the current sample. Individuals in the sample were asked to rate on a 0-100 scale *'how would you rate your quality of life?'* Higher scores on the item indicated higher levels of self-reported quality of life.

5.4.2.4 Clinical Recovery

5.4.2.4.1 Mental Health Inventory - 5 (MHI-5)

The MHI-5 is a five item self-report screening measure, which measures an individual's mental health status (Berwick et al., 1991). Derived from the 18 item MHI, the brief version uses a six-point rating scale ranging from 'none of the time' to 'all of the time', where two items are reversed scored. Higher scores are indicative of poorer mental health. The MHI-5 has good psychometric properties with high internal consistency (alpha= 0.88) and construct validity (McCabe, Thomas, Brazier, & Coleman, 1996).

5.4.2.4.2 World Health Organisation Disability Assessment Scale (WHODAS 2.0)

Item H2 from the WHODAS 2.0 was used in the study to measure difficulties with daily functioning (Ustun, 2010). This item was a continuous measure and asked *'how many days were you totally unable to carry out your usual activities or work because of any health condition?'* in the past 14 days. This item has previously been used in research in understanding functioning in individuals with BPD (Keely, Flanagan, & McCluskey, 2014; Miller, Lewis, Huxley, Townsend, & Grenyer, 2018).

5.4.3 Data Analysis

Data cleaning and screening was conducted prior to analysis using IBM SPSS Statistics 23. Descriptive statistics were conducted to describe the sample, whilst t-tests and chi-squared tests were used to identify between group differences. Pearson's correlations were conducted to understand associations between variables. Significant bivariate associations with dependent variables were further investigated using multiple regression, logistic regression, and multivariate analysis of variance (MANOVA). A significance level of 0.05 was selected for all analyses.

To further understand an individual's self-identified recovery status, the definitions provided by all included participants from the online survey were qualitatively analysed using an inductive thematic analysis to explore individual definitions of recovery. This was guided by a six-step process outline by Braun and Clarke (2006). Personal recovery definitions were obtained through an open text response dialogue as part of the online survey. This data was entered verbatim into NVivo 11. Researchers then familiarised themselves with the data by reading and reflecting upon responses. Data was first tagged with representative codes, then

codes of a similar nature were then combined to develop overarching themes. These themes were reviewed by the research team and cross-checked with the original participant responses to ensure the themes were representative of the participant responses. The data was coded independently by the first author and 20% of the data was coded by a second rater (MT) (inter-rater reliability = 82%). Disagreements between the coders were resolved via consensus.

5.5 Results

Demographic and clinical variables for the sample are reported in Table 8, along with the comparisons of individuals reporting being in the recovered compared to the not recovered group. A two-way between groups analysis of variance (ANOVA) revealed no significant differences between recovery status, diagnostic status and demographic variables (age, years of education or length of treatment). Chi-squared analyses revealed that individuals who self-identified with being recovered and met criteria for BPD were more likely to be engaged in paid work than individuals who self-identified with being recovered and did not meet criteria for BPD (χ^2=4.47, p=0.03). No other significant differences were identified (See Table 8)

5.5.1 Diagnostic Status

A total of 314 individuals (90%) met MSI criteria for BPD, whilst the remaining 35 individuals (10%) did not meet criteria. Individuals who did not meet criteria for BPD were significantly older (t=-2.10, p=0.04) and more likely to be in a relationship (χ^2=4.85, p=0.03). As expected, significant differences between groups were identified on all domains of clinical and personal recovery, with individuals who did not meet criteria for BPD scoring higher on personal recovery outcomes and lower on clinical outcomes.

As outlined in Table 9, a weak yet significant correlation between the number of items endorsed on the MSI and relationship status, self-identified recovery status, total MHI-5 score, the number of disability days and all domains of personal recovery was identified.

Significant associations were inputted into a multiple linear regression analysis to further explore the relationship between diagnostic status, demographic, clinical and personal recovery variables (See Table 10). The overall model predicting the number of MSI items endorsed by individuals with BPD was significant (R^2= 0.188, F(11, 315)=6.62, p=0.00), with age (β=-0.113, p=0.03), relationship status (β=0.185, p=0.00) and total MHI-5 score (β=0.246, p=0.002) individually predictive of total number of MSI items endorsed by individuals.

5.5.2 Self-Identified Recovery Status

A total of 73 individuals (20.9%) identified themselves as being recovered and the remaining 276 individuals (79.1%) did not identify with being recovered. A greater proportion of individuals who identified with being recovered were engaged in paid employment (χ^2=31.91, p=0.03) and worked significantly longer hours per week (t=5.26, p=0.00). Individuals self-identified with being recovered scored significantly higher on all domains of personal recovery, indicating higher levels of personal recovery and quality life. The reverse was observed on domains of clinical recovery, with lower scores endorsed indicating better mental health (See Table 8).

Self-identified recovery status was significantly correlated with employment status, hours of work per week and all domains of clinical and personal recovery. Significant associations were further investigated in a binary logistic regression, which revealed an overall significant

model (χ^2=144.333, df=11, p=0.00), however no individual variables significantly predicted self-identified recovery status (See Table 11).

Table 9. Zero-order correlations for demographic, clinical and personal recovery domains

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
1. Age	-																		
2. Gender	0.132*	-																	
3. Years of Education	0.058	-0.100	-																
4. Years of Treatment	0.391*	-0.022	0.075	-															
5. Relationship Status	-0.049	-0.136*	-0.033	-0.042	-														
6. Employment Status	0.032	0.119	-0.139*	0.115*	0.008	-													
7. Hours of Work per Week	0.005	-0.035	0.137*	-0.101	0.021	-0.754**	-												
8. Age of onset	0.283**	0.129*	0.030	-0.005	-0.089	0.004	0.003	-											
9. Age of diagnosis	0.817**	0.102	0.073	0.206**	-0.081	-0.035	0.059	0.305**	-										
10. Number of MSI items met	-0.134*	0.044	-0.086	-0.077	0.159**	0.010	-0.040	-0.027	-0.088	-									
11. Self-Identified Recovery Status	-0.093	0.103	-0.075	-0.033	-0.029	0.311**	-0.283**	0.015	-0.049	0.152**	-								
12. RAS-DS Total	0.030	-0.119*	0.116*	0.103	0.009	-0.206**	0.172**	-0.031	0.028	-0.261**	-0.522**	-							
13. RAS-DS Things I Value	0.031	-0.128*	0.085	0.122*	-0.006	-0.095	0.067	0.025	0.031	-0.127*	-0.345**	0.762**	-						
14. RAS-DS Looking Forward	0.040	-0.073	0.102	0.081	0.026	-0.175**	0.158**	-0.028	0.036	-0.243**	-0.500**	0.949**	0.659**	-					
15. RAS-DS Mastering Illness	0.080	-0.068	0.027	0.066	-0.021	-0.241**	0.185**	-0.042	0.054	-0.264**	-0.561**	0.854**	0.520**	0.769**	-				
16. RAS-DS Connecting and Belonging	-0.063	-0.181**	0.195**	0.112*	0.001	-0.189**	0.158**	-0.047	-0.034	-0.223**	-0.304**	0.749**	0.515**	0.579**	0.559**	-			
17. Quality of Life	0.002	-0.126*	0.141*	0.017	0.077	-0.232**	0.209**	0.019	0.006	-0.220**	-0.414**	0.622**	0.481**	0.582**	0.555**	0.455**	-		
18. MHI-5	-0.130*	0.073	-0.071	-0.108*	-0.080	0.180**	-0.148**	0.004	-0.088	0.333**	0.479**	-0.678**	-0.520**	-0.665**	-0.622**	-0.410**	-0.590**	-	
19. Number of Disability Days	0.048	0.119*	-0.056	0.080	-0.044	0.359**	-0.365**	-0.093	-0.019	0.223**	0.318**	-0.294**	-0.193**	-0.274**	-0.291**	-0.214**	-0.407**	0.405**	-

N=349. Gender (0=Female, 1=Male), Relationship Status (0=not in a relationship, 1= in a relationship) and Employment Status (0=Employed, 1=Not Employed)

*p<0.05, **p<0.01

Table 10. Multiple linear regression predicting number of MSI items endorsed by demographic, clinical and personal recovery variables

	B	β	t	p	CI
Self-identified recovery status	-0.184	-0.039	-0.622	0.534	[-0.764, 0.397]
Age	-0.020	-0.113	-2.156	0.032*	[-0.038, -0.002]
Relationship Status	0.704	0.185	3.603	0.00**	[0.320, 1.088]
RAS-DS Total	-0.245	-1.783	-0.568	0.570	[-1.092, 0.602]
RAS-DS Things I Value	0.052	0.421	0.731	0.465	[-0.088, 0.193]
RAS-DS Looking Forward	0.111	0.924	0.568	0.570	[-0.274, 0.496]
RAS-DS Mastering Illness	0.037	0.335	0.448	0.654	[-0.126, 0.200]
RAS-DS Connecting and Belonging	0.031	0.264	0.376	0.707	[-0.131, 0.193]
Quality of Life	0.000	-0.002	-0.030	0.976	[-0.012, 0.011]
MHI-5	0.094	0.246	3.158	0.002**	[0.035, 0.152]
Number of Disability Days	0.051	0.112	1.925	0.055	[-0.001, 0.104]

Table 11. Logistic regression predicting self-identified recovery status by demographic, clinical and personal recovery variables

	B	SE	Wald	df	p	OR	CI
Employment Status	0.585	0.577	1.028	1	0.311	1.794	[0.580; 5.554]
Hours of Work per Week	-0.024	0.016	2.117	1	0.146	0.976	[0.945; 1.008]
Number of MSI items met	-0.057	0.091	0.387	1	0.534	0.945	[0.791; 1.129]
RAS-DS Total	0.412	0.913	0.204	1	0.652	1.510	[0.252; 9.047]
RAS-DS Things I Value	-0.069	0.149	0.214	1	0.644	0.933	[0.696; 1.251]
RAS-DS Looking Forward	-0.211	0.416	0.258	1	0.612	0.809	[0.358; 1.830]
RAS-DS Mastering Illness	-0.150	0.175	0.731	1	0.392	0.861	[0.610; 1.214]
RAS-DS Connecting and Belonging	-0.062	0.175	0.124	1	0.725	0.940	[0.667; 1.325]
Quality of Life	-0.017	0.013	1.641	1	0.200	0.984	[0.959; 1.009]
MHI-5	0.076	0.055	1.892	1	0.169	1.079	[0.968; 1.203]
Number of Disability Days	0.123	0.066	3.492	1	0.062	1.131	[0.994; 1.286]

Individual definitions of recovery in BPD illustrated two differing conceptualisations 1) recovery as self-management, and 2) recovery as not possible or individuals were unsure of their definition. The majority of individuals described recovery as self-management where recovery occurred *'within BPD. My personality disorder will always be a part of me even if I learn to control it because it is my personality'* (JTR174). Self-management was comprised of a number of factors including the management of symptoms in order to reduce impact on daily living *'to me recovery from BPD is the process of learning to deal with emotions, destructive behaviours and people in a more healthy way that would improve my quality of life… I don't think recovery has anything to do with being completely free of all symptoms. I think BPD is part of who I am and will always be there in some way'* (JTR129). For some individuals this involved the use of coping strategies, such that *'recovery is having the tools/skills you need to process overwhelming emotional responses. Recovery is being able to react to situations in a healthier way than 'fight or flight''* (JTR121). However, some individuals reported the desire for the amelioration of specific symptoms such as self-harm and suicidal ideation or to no longer meet the diagnostic criteria. For example to have *'no more suicidal thinking.*' (JTR575) or *'recovery occurs when a person no longer meets the minimum criteria to be diagnosed with BPD. That is to say, their behaviour and thinking patterns have changed so drastically that they meet fewer than the number of criteria required.'* (JTR117). A sense of comfort and acceptance of oneself was desired such that *'I don't define it [recovery] a behavioural reduction. To me it has to be more internal – inner contentment and desired to continue living a life that feels worth living'* (JTR137).

The process of self-management was described to be ongoing and fluctuating with individual definitions highlighting the non-linearity of the process. Recovery was considered to be *'a journey without a specific end point, I could at some point begin to experience more severe*

symptoms again, though that doesn't equate to failure, just a setback that I can work through' (JTR162).

A small proportion of individuals noted that recovery in BPD was not possible for them or were unsure of the definition. A sense of hopelessness and disbelief in the possibility of recovery was associated with the continual experience of symptoms. Some participants noted that *'recovery doesn't exist. I will never be able to recover in the sense that I will never not endure BPD symptoms'* (JTR527) or *'I don't believe it is possible'* (JTR034). Individuals unsure of the definition reported *'not sure how I would define recovery as still in the process'* (JTR089) or simply that *'I still don't know'* (JTR378).

5.5.3 Diagnostic Status and Self-Identified Recovery Status

Most individuals met criteria for BPD and did not identify with being recovered (n=252, 72.2%) or identified with being recovered (n=62, 17.8%). The remaining individuals did not meet criteria for BPD and did not identify with being recovered (n=24, 8.7%) or identified with being recovered (n=11, 3.2%). A significantly greater proportion of individuals who self-identified with being recovered and met criteria for BPD were in paid employment compared to those who individuals who self-identified with being recovered and no longer met criteria (t=4.47, p=0.03). Expectedly, individuals differed significantly on the number of MSI items endorsed.

Individuals who self-identified with being recovered did not significantly differ on any clinical or personal recovery domains, regardless of diagnostic status. On the contrary, individuals who self-identified with not being recovered significantly differed on all domains except the Looking Forward domain on the RAS-DS (t=-1.90, p=0.07), with individuals who

did not meet criteria scoring higher on personal recovery and lower on clinical recovery domains (See Table 8).

To further investigate group differences, a series of two-way (diagnostic status x self-identified recovery status) multivariate analysis of variance (MANOVAs) were performed on clinical and personal recovery domains. Self-identified recovery status demonstrated a significant main effect on clinical and personal recovery outcomes at the $p<0.01$ level (See Table 12). A significant main effect of diagnostic status was identified only for clinical recovery only ($F(2,326)=7.690$, $p=0.001$, Roy's largest root= 0.047, partial eta squared=0.045). Univariate analyses confirm the t-tests reported in Table 8. Whilst no significant interactions for personal or clinical recovery were identified in the MANOVA model, univariate analysis revealed a significant interaction between self-identified recovery status and diagnostic status on the total MHI-5 score ($F(1,327)=5.018$, $p=0.026$, partial eta square=0.015).

Table 12. MANOVA results for each recovery domain including main and interaction effects

Recovery Construct	**Effect**	**Roy's Largest Root**	**F**	**p**	**Partial Eta Squared**
Personal Recovery	Self-Identified Recovery Status	0.185	12.378	0.00**	0.156
	Diagnostic Status	0.024	1.621	0.154	0.024
	Interaction	0.016	1.038	0.395	0.015
Clinical Recovery	Self-Identified Recovery Status	0.101	10.935	0.00**	0.092
	Diagnostic Status	0.047	5.116	0.002**	0.045
	Interaction	0.016	1.779	0.151	0.016

Note: ** significant at the 0.01 level, * significant at the 0.05 level

5.6 Discussion

This study aimed to explore the differences in clinical and personal recovery outcomes in 349 individuals with BPD when applying three different criteria; 1) diagnostic status only, self-identified recovery status only or, 3) combined diagnostic and self-identified recovery status. The results showed that there was concordance between diagnostic status and self-identified recovery status in 75.4% of the sample and only a small group (11 individuals) who identified with being self-identified recovered and no longer meeting criteria for BPD. This finding may be reflective of several considerations; first, the definitions used in the study to assess for diagnostic status and self-identified recovery status may be difficult to achieve for most people. This is reflected in other studies, where significantly less individuals meet stricter definitions of recovery (Zanarini et al., 2018; Zeitler et al., 2018). However, it is important to note differences between methodologies between assessing for recovery. The present study asked individuals for their perceived recovery status based on their own definition of recovery, whilst other studies used objective measures of functioning or life satisfaction (Zanarini et al., 2018; Zeitler et al., 2018). Secondly, the recruitment techniques used may have contributed to a skew in the types of individuals who participated. Convenience sampling was used to recruit individuals from online sources, particularly those sources with a focus on supporting individuals with mental health concerns. The plethora of online resources and stigma (Veysey, 2014) may contribute to more individuals assessing support online. Therefore, it is plausible that individuals were actively seeking support or at an earlier stage of recovery. However, the implications of identifying oneself as recovered should also be considered. Given difficulties with accessing services (Lawn & McMahon, 2015) and attachment difficulties (Agrawal, Gunderson, Holmes & Lyons-Ruth, 2004), considering oneself as recovered may lead to a potential risk in the loss of services or valued therapeutic relationships.

Whilst the explanatory power of the model was low, age and relationship status were predictive of diagnostic status. Older individuals endorsed less items on the MSI-BPD, which suggests that the experience of some BPD symptoms may reduce with age (Stevenson, Meares & Comerford, 2003). Yet, this may also reflect a treatment effect, as years of treatment was positively associated with age. Interpreting the relationship status finding requires more careful consideration. Interpersonal difficulties are characteristic of BPD (Sanislow et al., 2002), therefore, it is expected that individuals who meet criteria for BPD may have difficulties within relationships. Although individuals who did not meet criteria endorsed higher scores on the Connecting and Belonging domain of the RAS-DS, suggesting that they may have a stronger support network, the study did not examine the quality of relationships engaged in by individuals, which may provide a stronger indication of the impact of relationships on diagnostic status.

This is the first study known to researchers which utilised an individual's definitions of recovery as a measure within the context of BPD. Individuals who do not self-identify with being recovered endorsed significantly more items on the MSI-BPD. Yet the scores of individuals who self-identified with being recovered also indicated the presence of BPD. This is an interesting finding suggesting that meeting criteria for BPD does not preclude individuals to considering themselves as recovered. Whilst this supports the notion that personal and clinical recovery are related yet distinct constructs (Lloyd, King & Moore, 2010; Roe, Mashiach-Eizenberg & Lysaker, 2011; Tse et al., 2014; Resnick, Rosenheck & Lehman, 2004), correlational findings in the study suggest that clinical and personal recovery domains within individuals with BPD are related yet less distinct compared to other severe mental illnesses. The overlap between the clinical phenomenology of BPD and domains of personal recovery identified within personal recovery frameworks may be a contributing factor to this finding (Shepherd et al., 2017; Leamy et al., 2012; Sanislow et al., 2002).

Interestingly, no variables included in the logistic regression analysis was predictive of an individual's self-identified recovery status. The MANOVA, however, identified that an individual's self-identified recovery status was identified to have a significant effect on domains of clinical and personal recovery measured in this study, whilst diagnostic status only influenced clinical recovery domains. Therefore, an individual's perceived recovery status appears to be an important consideration, however, the question of what makes an individual consider themselves as recovered remains.

Thematic analysis revealed that individuals defined recovery in BPD as a process involving the self-management of symptoms and engagement in meaningful daily living. Consistent with other qualitative studies examining the lived experience of recovery in BPD (Katsakou et al., 2012; Larievere et al., 2015; Shepherd et al., 2017; Ng et al., 2019; Gillard, Turner & Neffgen, 2015), the broad definition of recovery provided by individuals highlights the multi-faceted nature of recovery, incorporating both symptom reduction and psychosocial aspects, supporting the complimentary nature of clinical and personal recovery paradigms (Davidson & Roe, 2007). This conceptualisation of recovery also illuminates the concerns raised by other qualitative studies, where 'process' or 'journey' have been proposed as better alternatives (Katsakou et al., 2012; Shepherd et al., 2017). Yet, this definition also highlights that the use of a dichotomous variable for self-identified recovery status in this study may be too narrow, given the nuances identified by individuals.

The need to consider factors beyond clinical recovery may be demonstrated in the finding that individuals who self-identify with being recovered, do not significantly differ on clinical or personal recovery domains, despite differences in diagnostic status. This is an interesting finding as it suggests that an individual's perception of their recovery may be a strong influencer of clinical and personal recovery outcomes. This supports findings of a systematic

review which suggests that positive expectations for recovery is related to better health outcomes (Mondloch, Cole & Frank, 2001). The contributions of empowerment in BPD have been highlighted in a recent study exploring alternative methods of assessing recovery in BPD, where the incorporation of measures of life satisfaction were recommended as a better indicator compared to objective ratings of psychosocial function (Zeitler et al., 2018). It is suggestive that considering an individual's perspective, life satisfaction and level of hope may be important in evaluating outcomes in individuals with BPD. This may be an important consideration for clinical practice, such that it may be beneficial for clinicians to enquire about an individual's recovery definition and their perception of progress.

5.6.1 Strengths and limitations

This study consisted a large sample size however a limitation is that participants were drawn from those engaged in social media or online groups. Future research should balance this with population studies and studies of those seeking and receiving health services. All individuals reported having previously been diagnosed with BPD from a health professional, although this could not be verified as researchers did not have access to medical records. Similarly, although a reliable and valid screening tool was used to validate current BPD diagnosis, a more effective strategy for future studies would be to re-assess individuals through structured clinical assessment. The numbers of people recovered and not symptomatic, was far smaller than the rest of the sample, thus future research could aim to have a more balanced sample across subgroups.

The cross-sectional design of the study does not provide understanding of the causal effects of an individual's self-identified recovery status on outcomes. Given the finding that recovery is fluctuating, this could affect results collected using one time point. The qualitative findings support this finding such that individuals considered recovery as a process, suggesting that

recovery may occur across different stages. Phenomenologically, the stages of recovery through the perspectives of individuals with lived experience of BPD is unknown. Future qualitative and quantitative research could examine whether there are specific stages associated with recovery, and use longitudinal or ambulatory assessment methods to understand recovery over extended periods of time. Additionally, individuals in this study were asked to indicate whether they self-identified with being recovered or not recovered. This may be too simplistic in nature, as responses from the qualitative analysis indicates that recovery is a more complex process, which may not be captured by a dichotomous rating. Whilst it is acknowledged that the empirical evaluation of recovery is necessary for the development of the field, the inclusion of differing research methods, such as case studies may provide additional insights.

CHAPTER SIX

Phase Four

The Lived Experience of Recovery in Borderline Personality Disorder: A Qualitative Study

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Ng, F.Y.Y., Townsend, M.L., Miller, C.E., Jewell, M, & Grenyer, B.F.S. (2019). The lived experience of recovery in borderline personality disorder: A qualitative study. *Borderline Personality Disorder and Emotion Dysregulation. 6*(10), 1-9. doi: 10.1186/s40479-019-0107-2

The full manuscript is included as Appendix O. Additional illustrative quotes for each stage and process identified in the analysis is presented as Appendix P. This is presented to provide additional supporting evidence of the themes identified in the qualitative analysis. Borderline Personality Disorder and Emotion Dysregulation is an open access journal, therefore this manuscript was published as an open access article which can be distributed under the terms of the Creative Commons Attribution License, provided the authors and source are cited.

6.1 Preface

In Chapter Three, the findings confirmed that there is no clear understanding about the different stages of recovery through the perspectives of individuals with lived experience. Whilst there is some indication of the processes which may be involved during the recovery journey as identified through an individual's treatment and recovery goals (Chapter Four), these do not provide a clear understanding of the relationship between the stages and processes. This is further supported by findings in Chapter Five, which found that an individual's perception of their own recovery progress can have significant impacts on their clinical and personal recovery outcomes. There is also limited knowledge on how individuals at different stages of recovery differ.

Chapter Six reports on a qualitative study which examined the lived experience of recovery through the perspectives of 14 individuals with BPD at opposite ends of the recovery continuum.

6.2 Abstract

Objective: The concept of recovery in borderline personality disorder (BPD) is not well defined. Whilst clinical approaches emphasise symptom reduction and functioning, consumers advocate for a holistic approach. The consumer perspective on recovery and comparisons of individuals at varying stages have been minimally explored.

Method: Fourteen narratives of a community sample of adult women with a self-reported diagnosis of BPD, were analysed using qualitative interpretative phenomenological analysis to understand recovery experiences. Individuals were at opposite ends of the recovery continuum (seven recovered and seven not recovered).

Results: Recovery in BPD occurred across three stages and involved four processes. Stages included; 1) being stuck, 2) diagnosis, and 3) improving experience. Processes included; 1) active engagement in the recovery journey, 2) hope, 3) engagement with treatment services, and 4) engaging in meaningful activities and relationships. Differences between individuals in the recovered and not recovered group were prevalent in the improving experience stage.

Conclusions: Recovery in BPD is a non-linear, ongoing process, facilitated by the interaction between stages and processes. Whilst clinical aspects are targets of specialist interventions, greater emphasis on fostering individual motivation, hope, engagement in relationships and activities, may be required within clinical practice for a holistic recovery approach.

Keywords: Borderline Personality Disorder, Recovery, Lived Experience, Qualitative

6.3 Introduction

Recovery in borderline personality disorder (BPD) has predominantly been viewed in the context of symptom improvement and no longer meeting diagnostic criteria. Longitudinal studies have demonstrated that symptom remission is a common occurrence, with remission rates ranging between 33-99% (Ng et al., 2016). Personal recovery however, adopts a holistic stance and views recovery as a process rather than a fixed outcome (Katsakou et al., 2012; Slade, 2009). Conceptual frameworks of personal recovery have synthesised the stages across the transtheoretical model of change, and processes into the CHIME framework (connectedness, hope, identity, meaning and empowerment) (Leamy et al., 2011). The application of personal recovery to individuals with BPD requires further exploration (Newton-Howes & Gordon, 2016).

Qualitative studies examining the experience of individuals with personality disorder describe recovery as involving the reconciliation of self and other representations, fostered through interpersonal relationships and integration within the community (Gillard, 2015; Shepherd et al., 2017). These views were similarly identified by Castillo and colleagues (Castillo, Ramon, & Morant, 2013) who described recovery as a hierarchical process, starting from the development of healthy attachment patterns, progressing to a state of transitional recovery. This process encompassed stages including, the sense of belonging, and development of hope, goals, identity and roles (Castillo et al., 2013). These stages were similar to the personal goals by Katsakou and colleagues (2012), which included aspects associated with regulating emotions and other symptoms. These findings were further confirmed in a study of treatment goals of individuals seeking treatment for BPD, where goals were identified to extend beyond the reduction of symptoms and included improving relationships, developing a sense a self and improving one's sense of wellbeing (Ng, Carter, Brouke, & Grenyer, 2019).

Whilst these findings indicate the treatment targets of manualised interventions may be narrow, there are innate difficulties in understanding recovery in personality disorders (Shepherd et al., 2017), given the similarities between clinical phenomenology and domains of personal recovery. The current changes to the conceptualisation of personality disorder from a categorical to dimensional approach, focusing upon individual traits, severity, and functioning, provides an opportunity to more fully integrate individual perspectives into treatment (Grenyer, 2017).

The perspectives of individuals accessing specialist treatment have been well represented within the literature. While important, a broader approach to include individuals who do not access specialist services, such as who have difficulty accessing services or no longer require services may provide a more holistic and representative view. This coincides with calls to further understanding the experiences of people who are at the opposite ends of the process (Spaniol, 2002). Therefore, this study aims to understand the experience and conceptualisation of recovery in individuals with BPD who are at varying stages of the recovery process. Comparisons between individuals in the recovered and not recovered groups were made to illustrate differences.

6.4 Method

6.4.1 Participants and Inclusion

Individuals were initially recruited to take part in an online survey, via mental health organisations and social media. This method of recruitment has previously been used in other studies in examining the experience of personality disorder (Bailey & Grenyer, 2014).

The study's inclusion criteria was based on the recognition in the wider literature that recovery may occur across stages and is fluctuating in nature (Leamy et al., 2012; Andresen et al., 2003; Slade, 2009). A longitudinal study of individuals with schizophrenia identified that half the sample did not progress past the first stage ('overwhelmed by the disability'), and no individuals attained the final stage of recovery ('living beyond the disability') within the two-year follow-up period (Spaniol et al., 2000). Findings from a study examining recovery in BPD similarly identified the final stage ('recovered') to be more uncertain (Katsakou et al., 2012). Therefore, the perspectives of individuals at the extreme ends may be important to understand in order to capture what the recovery spectrum in BPD may entail.

Following completion of an online survey, researchers grouped individuals into one of four groups identified by recovery and diagnostic status. Recovery status was obtained through asking individuals to define recovery in BPD and identification with their personal definition. Diagnostic status was determined through the McLean Screening Instrument for Borderline Personality Disorder (MSI-BPD) (Zanarini et al., 2003a). The MSI-BPD is a 10-item self-report screening measure, where a score of 7 or greater indicates the high likelihood of meeting DSM-5 criteria for BPD. The MSI-BPD has good psychometric properties with high sensitivity (0.81), specificity (0.85) and reliability (alpha=0.74) (Zanarini et al., 2003a). The narratives of individuals who self-identified with being recovered and no longer met criteria for BPD (recovered group), and individuals who did not self-identify with being recovered and met criteria for BPD (not recovered group) were included in the study. Individuals were further matched on age, gender, and treatment history. Narratives were included into the study until thematic saturation was reached. This resulted in the inclusion of 14 individual narratives (n=7 recovered group and n=7 not recovered group). The study was approved by the University of Wollongong Social Sciences Human Research Ethics Committee and all individuals provided informed consent.

6.4.2 Data Analysis

Semi-structured interviews following a topic guide were conducted. The guide provided general prompts for the interviewer and was refined following consultation with a consumer advisory committee (see Appendix H). The interviewer asked individuals to describe their first experiences with BPD, current life, views of recovery, and experience of treatment and supports. Interviews were audio recorded, transcribed verbatim and entered into NVivo 11 for data analysis.

Interpretive phenomenological analysis (IPA) was used as the overarching methodology to understand individuals' experience and the ascribed meaning associated with the recovery journey in BPD (Smith & Osborn, 2009). Smaller sample sizes are recommended to gain in-depth understanding (Smith & Osborn, 2009). An inductive approach outlined by Smith and colleagues (2009) was used to understand the emergent themes and the relationship between themes. Firstly, researchers immersed themselves in the narrative by reading transcripts, whilst free coding to gain an overarching understanding of the data. Secondly, free codes were coded into emergent themes summarising excerpts of individual's narratives. Emergent themes were then clustered into superordinate themes to describe individuals' experiences. This process was supported by discussions by the research team, where discrepancies between the team were resolved via consensus. Two transcripts, which represented over 10% of the data were coded by two independent raters (FN and CM) (inter-rater reliability = 91%). The remaining data was independently coded by one researcher (FN). The names of individuals have been de-identified to their participant number for confidentiality purposes. Individuals in the recovered group are denoted with 'R' and those who are not recovered are denoted with 'NR'. Once the coding was determined by the researchers, the findings were

discussed with a member of the consumer advisory committee, whose feedback was integrated to strengthen the paper (MJ).

6.5 Results

A total of 171 individuals provided contact details for follow-up from the online survey, where 108 individuals were contacted. Thirty-nine individuals completed the telephone interview. Using the study's inclusion criteria, 14 individual narratives (7 recovered and 7 not recovered) were included in the study. All individuals in this study were female with an average age of 33.36 years (SD=10.26). The majority of individuals were from Australasia, with one individual from the Middle East. There were no significant differences on socio-demographic characteristics between the two groups. Comparison of socio-demographic characteristics of individuals are provided in Table 13.

Table 13. Comparison of socio-demographic participant characteristics

Variable	Statistic	Total (N=14)	Recovered Group (n=7)	Not Recovered Group (n=7)	t (p) or χ^2
Age	M (SD) Range	33.36 (10.26) R=18-52	33.43 (11.43) R=18-52	33.29 (9.88) R=22-46	0.03 (0.98)
Education (years)	M (SD) Range	14.29 (1.94) R=11-16	14.29 (2.29) R=11-16	14.29 (1.70) R=11-16	0.00 (1.00)
Employment status					
Engaged in paid work	% (n)	42.9 (6)	42.9 (3)	42.9 (3)	1.14 (0.57)
Relationship Status					
Single	% (n)	64.3 (9)	57.1 (4)	71.4 (5)	0.31 (0.58)
In relationship	% (n)	35.7 (5)	42.9 (3)	28.6 (2)	
Treatment Length (years)	M (SD) Range	12.68 (6.72) R=2-24	9.93 (9.47) R= 6-15	15.43 (5.00) R=9-21	-1.63 (0.13)
Age of Onset	M (SD) Range	9.71 (3.58) R=4-15	10.57 (3.55) R=6-15	8.86 (3.67) R=4-14	-0.36 (0.73)
Age of Diagnosis	M (SD) Range	25.57 (10.14) R=15-45	24.57 (9.47) R=16-44	26.57 (11.44) R=15-45	0.89 (0.39)
Gap between Onset and Diagnosis	M (SD) Range	15.86 (10.88) R= 6-38	14.00 (10.79) R= 7-38	17.71 (11.50) R= 6-34	-0.62 (0.55)

Note. No significant differences between recovered and not recovered groups

6.5.1 Stages of Recovery in Borderline Personality Disorder

Recovery in BPD occurred across three core stages, including; 1) being stuck, 2) diagnosis, and 3) improving experience. Differences between individuals in the recovered and not recovered groups were observed in the final stage of recovery continuum. The movement between stages fluctuated, therefore narratives were discussed from a current or retrospective stance. A graphical representation of the stages and processes of recovery in BPD is depicted in Figure 3.

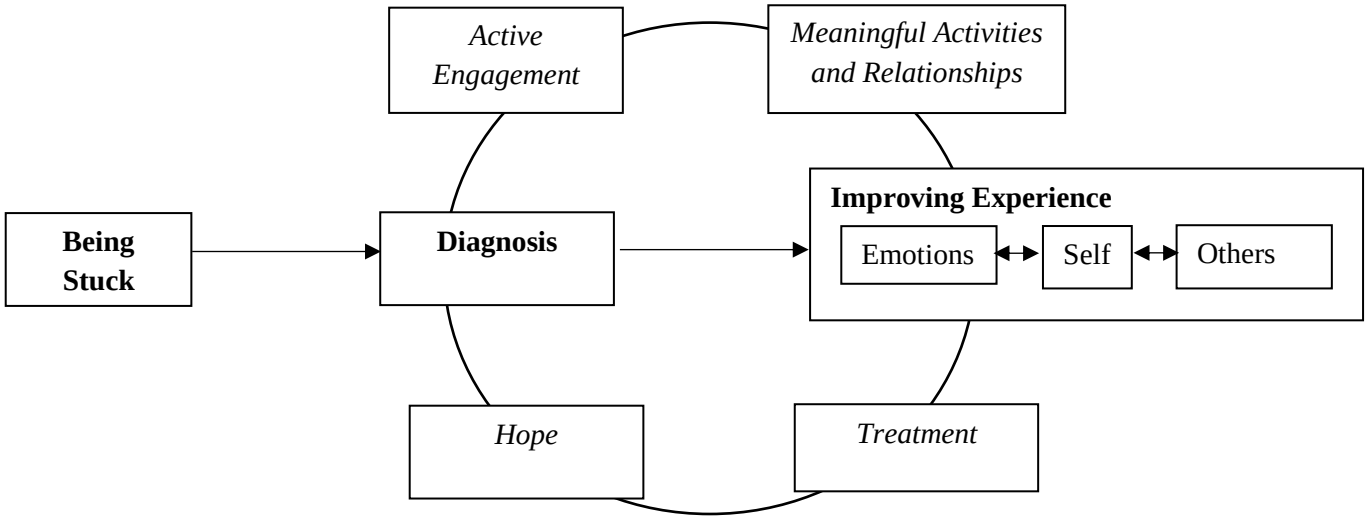

Figure 3. Stages and processes of recovery in borderline personality disorder

6.5.1.1 Being Stuck

This stage was characteristic of all individuals when first experiencing symptoms of BPD. Individuals did not have a clear conceptualisation of their experiences and described 'being stuck' as a state of *'floundering, getting bounced in and out of hospital… I was lacking in therapy and not really engaging in services'* (JTR191-R). An individual's emotional intensity was identified to impact upon daily living and was noted to extend beyond the realms of

normal experience, where *'emotions are so raw and powerful, they drove everything. I had no insight whatsoever into what I was doing. I didn't know who I was, what I was doing or why. I reacted to everything in an unhealthy way'* (JTR280-R). Reports of maladaptive coping strategies such as self-harm or repeated suicide attempts were prevalent at this stage.

Negative experiences from childhood and adolescence, such as bullying or abuse, was reported to affect an individual's perception about self and others. For example *'BPD can be rooted in childhood trauma… I was taught it was always my fault as a child. Being in a relationship now with the same thing happen, my brain will assume, it is my fault'* (JTR051 – NR). The enduring nature was also noted in interpersonal difficulties, such that *'even at six years old, I had that instable personality… Not having any kind of self-worth and switching from one friend to another depending on what my needs were and how that person was feeling…'* (JTR239 – R).

Unsuccessful attempts at seeking help for mental health concerns was also characteristic during this stage. Misdiagnosis of other mental health concerns, such as depression, anxiety and bipolar disorder, were a common experience. Individuals reported these diagnoses did not encapsulate the severity of their experience, as *'it felt much worse but they told me my problems are mild and not an issue'* (JTR051 – NR). The knowledge of health professionals and the ability to access effective treatments were viewed to be crucial for an individual to move on from the 'being stuck' phase.

6.5.1.2 Diagnosis

Receiving a diagnosis of BPD was identified to be a critical turning point in assisting individuals to conceptualise their experiences and emotional intensity. Diagnosis provided individuals a narrative *'to describe what was going on, that I wasn't alone and other people*

had experienced this as well' (JTR011 – R), giving individuals a sense of validation and relief, which assisted with progression in the recovery journey. The impact of delayed or mis-diagnosis was highlighted in the length of time taken to receive a diagnosis of BPD, as diagnosis assisted some individuals to gain access to evidence based treatment for BPD. Non-acceptance or disinterest in the diagnosis was reported by a minority of individuals, *'I didn't accept the borderline diagnosis. I wasn't interested and no one was interested in talking to me about it… but I understood what bipolar was and thought that did seem to fit'* (JTR239 – R). Some participants highlighted the immediate need for information about BPD to contextualise the diagnosis, as *'the worst thing is when people are not given any information when they are diagnosed with BPD.'* (JTR280 – R). Whilst knowledge was predominately acquired from engagement with health services, some individuals identified their own efforts to gain knowledge, *'I did a lot of reading once I got the diagnosis. It really made sense'* (JTR011 – R). However, the prevalence of stigma and discrimination associated with the diagnosis of BPD promoted negative experiences, where *'I've had some really traumatic experiences as a result of having the diagnosis… I no longer seek help if I'm in crisis, because I know that I'll get treated badly and be more stressed than if I didn't do anything...I feel like I don't trust the system'* (JTR051 – NR).

6.5.1.3 Improving Experience

Developing greater awareness of emotions and of self and others was described as a core stage and influencer of recovery. Three domains were associated with this stage including 1) Developing Greater Awareness of Emotions and Thoughts, 2) Strengthening Sense of Self, and 3) Understanding the Perspectives of Others. These domains were not mutually exclusive, yet the progression made in this stage differed between individuals.

Individual's conceptualisation of recovery indicated that there was scepticism surrounding the amelioration of symptoms. Recovery was considered an ongoing journey with elements of survival, resilience and self-management. For example, *'it can be managed… I don't think the symptoms will ever 100% disappear forever. They'll always be there to some degree in the background. I hope I get to a point where it doesn't impact on your life in a negative way'* (JTR051 – NR). This was echoed by individuals who identified with being recovered as, *'I got to a point where I realised that all that suffering made me much stronger. I have more insight because I had to do the work to recover'* (JTR280 – R).

6.5.1.3.1 Developing Greater Awareness of Emotions and Thoughts

The identification of emotions and thoughts was considered a starting point in fostering understanding of oneself and the use of coping strategies, such that *'I was beginning to develop more awareness of my emotions, but not so much control. Just the ability to not be blindsided by them'* (JTR459 – NR). However, the identification of emotions did not preclude individuals to distress, where *'I don't necessarily act on my thoughts anymore. My first reaction to something will be 'I should self-harm', but even though I'm not actually physically doing it, having my thoughts consumed by it is distressing'* (JTR083 – NR).

6.5.1.3.2 Strengthening Sense of Self

All individuals acknowledged that developing one's sense of self was a central component of the recovery journey. Individuals who identified with being recovered provided greater details of the nuances of developing a stronger sense of self. This was conceptualised as a process of reframing how one understands or perceives oneself. This process was noted to commence in conjunction with developing skills to recognise and tolerate emotions.

Individual narratives discussed the lack of identity stemming from first experiences of BPD and their sense of self being constructed upon symptom experience and identification with the BPD diagnosis. For example; *'Sometimes I feel like my whole identity has been based around my trauma… and when you suddenly start being able to react differently to things, I kind of felt like a lot of my identity was disappearing, because I no longer feel as intense'* (JTR051 – NR). Stigma arising from interactions with others had the potential to reinforce negative self-perceptions, such that *'I was very reluctant to actually disclose to people [my diagnosis] up until only really a few years ago, because I disclosed previously without thinking about it and then experienced unpleasant responses.'* (JTR011 – R).

Being aware of individual patterns and triggers provided opportunities to *'always challenge myself to become better. Instead of avoiding things like I used to, I think about how I can do it until I'm not stressed out by it anymore'* (JTR233 – R). This allowed for skill practice but also a subsequent sense of agency. Difficulties moving away from the illness identity was articulated by a minority of individuals in the recovered group. Despite progress made in identifying emotions and skill usage, individuals noted that *'my therapist had been telling me that I was recovered and I didn't meet criteria, but I didn't believe her. I think it was because I lacked an identity. I still don't understand what identity is… I held onto that diagnosis for such a long time, that was who I was'* (JTR239 – R). The fear associated with developing a greater sense of self exacerbated this as *'what if I use the skills and do what I need to do to achieve recovery and I still hate myself?'* (JTR280 – R).

6.5.1.3.3 Understanding the Perspectives of Others

This theme was discussed by a minority of individuals in the recovered group. Individuals described this as a process of reflecting beyond one's own subjective experience to include the capacity of others and the relational context. The impact of being able to understand the

perspectives of others in reconciling relationships was highlighted in an individual's response, where *'I got to experience the pain that I inflicted on my mother, by projecting all my self-loathing onto her. My mum had her own weaknesses… but I was too caught up in my own narcissistic injuries before to conceptualise how much pain I'd caused her.'* (JTR191 – R). This was similarly discussed by another individual, where the perspectives of others allowed for the calibration of her own perceptions of self. For example *'My husband always saw my potential and knew what I'm capable of, but I didn't see that at the time. I just thought he was ridiculous and was making fun of me, but I now know what he means'* (JTR072 – R).

6.5.2 Processes of Recovery in Borderline Personality Disorder

Four recovery processes in BPD were identified from individual's narratives; 1) active engagement in the recovery process, 2) hope, 3) treatment and, 4) meaningful activities and relationships. These processes could be overlapping and facilitate or hinder the recovery journey. Some differences between individuals in the recovered and not recovered groups were identified. These recovery processes contributed to the movement through the recovery stages and the growth within individuals.

6.5.2 1 Active Engagement in the Recovery Process

The desire and willingness to engage in the recovery process was crucial for progress in recovery to be made. Yet these observations were often made from a retrospective standpoint, when individuals had already accepted their diagnosis and take *'responsibility to learn the skills and do it yourself, you're going to get to a finite point, where it's all going to be ok'* (JTR011 – R). Motivational differences between individuals in the recovered and not recovered groups were identified, such that individuals in the recovered group placed

emphasis on intrinsic factors, whilst individuals in the not recovered group emphasised extrinsic factors. A minority of individuals identified that the mindset in which they approached treatment may impact on willingness to active engage in recovery such that a change-oriented mindset was necessary. *'I was in treatment but I thought why I was sitting there listening to other people talk about their issues. I thought this isn't my problem and I felt so angry, I didn't see the point, so I dropped out.'* (JTR239 – R).

6.5.2.2 Hope

Hope was an overarching concept, permeated when experiences positively contrasted to individual perceptions or their worldview. Recovery was considered unexpected and promoted a new outlook which was not previously considered by some individuals. States of hopelessness particularly observed during the early stages was prevalent in all individuals, such that *'I didn't have any kind of hope. I didn't have anything to hold onto…'* (JTR239 – R). Hope could be generated through vocational and relational engagement and the subsequent sense of agency gained from the use of skills or reflection on progress. For some individuals in the not recovered group, the maintenance of hope was associated with the ability to get treatment, *'I had a wonderful psychologist who I got along really well with. But at the moment it's hard to keep my eye on the prize, per se'* (JTR459 - NR).

Hope played a role in the maintenance of motivation, as it contributed to gains in self-belief and the reduction of self-doubt. *'That sense of just knowing the emotions will end, this isn't a permanent thing... I used to feel like it was just never going to end'* (JTR239 – R). The shift in perspective had a compounding effect on individuals and their clinicians, as *'...I suppose I wouldn't expect it (recovery). I mean my clinicians were surprised by my recovery'* (JTR151 – R).

6.5.2.3 Treatment

Seeking treatment was identified by all individuals as a key component in the recovery process, where effective treatment aligned with individual goals provided a sense of hope and the development of skills. Whilst these provided individuals a sense that *'this could be working. Maybe things will be ok'* (JTR061 – NR), services and treatments were described as mixed and fragmented. All individuals described at least one negative experience, where difficulties accessing treatment hindered progress on recovery. Individuals described greater difficulties when at the start of the recovery continuum.

Incongruent relationships through a lack of therapeutic alliance between clinician and individual also contributed to a lack of progress made in recovery, such that *'I don't think I progressed much with them (clinician) because we didn't fit well'* (JTR051 – NR). This contrasted to the progress made with clinicians who promoted collaborative and trustworthy relationships, as these fostered stronger relationships, *'she would make an appointment with me and I wouldn't turn up. She didn't get angry… she just kept trying and waited until I was ready'* (JTR233 – R).

6.5.2.4 Meaningful Activities and Relationships

Engaging in meaningful activities and relationships was described as providing a sense of belonging and connectedness, the opportunity to practice new skills, reflect upon one's emotional reactions and sense of self. Although individual differences influenced what was considered meaningful, these commonly included employment, education, and relationships with friends, family, significant others and clinicians. Benefits such as the independence gained from being employed and the sense of *'affirmation and sense of purpose'* (JTR011-R) was discussed.

For some individuals during the early experiences of BPD, their experience of symptoms precluded their participation in activities such that when *'when I was a student and before I started working full-time, it was much harder and my symptoms were more pronounced. I had a lot more difficulty'* (JTR011-R). This also extended into the relational domain, where some individuals avoided relationships in fear of the negative effects on symptoms, such that *'I haven't had a relationship for the last seven months, it's easier when you don't have one… I'm really scared of actually going into a relationship again, because when that goes bad, I'm going to go bad.'* (JTR018 – NR).

All individuals acknowledged the role activities and relationships had for self-exploration and reflection. For example, meditation was described by one individual as *'a laboratory that helps you sit with yourself and watch how the emotions just rise and fall away'* (JTR191 – R). Whilst others identified differences in self in differing contexts, for example *'At work I would be fine, but I can be a complete mess outside of work. I can organise 10 other people but then my brain just switches. As soon as I don't have something to focus on, I focus on myself, which is bad.'* (JTR018 – NR). Noticing differences in oneself provided opportunities to gain greater insight into oneself.

6.6 Summary of Research Results

Overall, the findings indicate that:

- Recovery occur across three stages: 1) being stuck, 2) receiving a diagnosis, and 3) improving experience. The last stage consisted of three domains: a) developing greater awareness of emotions and thoughts, b) strengthening sense of self, and c) understanding the perspectives of others.

- The average time to move from being stuck to diagnosis was approximately 16 years, indicating that there may be a knowledge gap or stigma from clinicians contributing to this delay in diagnosis.
- In the final stage, 'improving experiences' differences were noted between individuals in the recovered and not recovered groups, with the former better able to describe the development of their sense of self and understanding of others.
  Four processes supported recovery and included: 1) active engagement in the recovery process, 2) hope, 3) treatment, and 4) meaningful activities and relationships. Progress through recovery occurred through the interaction between stages and processes.

6.7 Discussion

The present study aimed to gain a holistic understanding of recovery in individuals with lived experience of BPD at either end of the recovery continuum. Overall, recovery was characterised by an interaction between the stages and processes. The identification of recovery in BPD as an ongoing journey is reflective of current literature on personal recovery in mental health (Anthony, 1993; Katsakou et al., 2012).

The stages of recovery identified in the present study align with the broad recovery stages mapped by Leamy and colleagues (2011). However, stages identified were framed by individuals in a clinical manner. Domains associated with improving experience were reflective of core psychopathology in BPD (Sanislow et al., 2002). This mimics the tasks identified in other qualitative studies examining recovery in personality disorder (Gillard, 2015; Katsakou et al., 2012; Shepherd et al., 2017). Therefore, the developed framework may be reflective of recovery within the context of treatment. Individuals in this study on average

had 10 years of treatment, therefore the importance of treatment as part of recovery is not without standing. Yet, the literature proposes that there are multiple routes to recovery, including engagement in non-traditional mental health services (Slade, 2009), The possibility of individual recovery through the use of other supports, such as peer workers or recovery colleges, could be further investigated within the context of personality disorder.

As individuals were required to have a diagnosis of BPD to take part in the study, the being stuck and diagnosis stages were universally described. Diagnosis played a role in shifting the trajectory of experience and provide opportunity to formulate meaning and promote hope. However, the gap between an individual's perceived age of onset and age of diagnosis in this sample was approximately 15 years. This may be representative of a knowledge gap in health professionals and the need to upskill clinicians in working with people with personality disorder or stigma which may prevent timely diagnosis (Grenyer, Ng, Townsend, & Rao, 2017; McCarthy, Carter, & Grenyer, 2013; Shepherd et al., 2017). This compounds with the desire of individuals for information about BPD at diagnosis.

Differences between the recovered and not recovered groups were most pronounced in the improving experience stage. The narratives of individuals in the recovered group articulated experiences of understanding self and others, compared to individuals in the not recovered group who discussed working towards improving awareness of emotions and thoughts. Whilst growth is exemplified as a stage in other models of personal recovery, often involving self-management of symptoms (Andresen et al., 2003), narratives in this study indicate that the process of growth began through gaining awareness of emotions.

Strengthening the sense of self was identified to be a domain central to growth. There are differences between what is currently conceptualised as identity in the personal recovery literature, which proposes that individuals reformulate their sense of self (Bird et al., 2014;

Wisdom, Bruce, Auzeen Saedi, Weis, & Green, 2008), suggesting that individuals have some sense of self, prior to their first experiences of mental health concerns. In this study, individuals describe a lack of identity from first experiences of BPD. Adopting an illness identity has been associated with less favourable outcomes (Yanos, Roe, & Lysaker, 2010), whilst the movement away from illness identity is supported by the current personal recovery literature (Leamy et al., 2011). The emphasis on diagnosis in the current findings suggests that acceptance of the illness is required to a degree to progress in recovery in BPD. Over-identification however, can also lead to stagnation in recovery. Greater understanding of illness identity in BPD is required and is particularly salient given identity disturbances is core to the disorder. Identifying internal narratives may be a starting point in promoting motivation and willingness to engage in the recovery journey.

Engaging in relationships and meaningful activities is known to be a priority for individuals with BPD (Ng et al., 2016). Interestingly, the proportion of individuals engaged in paid employment and in a relationship did not significantly differ, despite individuals being at either end of the recovery continuum. This indicates that recovery status may have an influence on the quality of the relationship or the amount of work engaged in. Existing longitudinal studies have identified that approximately 50% of individuals experience 'good recovery' following 10 years of follow-up, indicating that individuals have experienced concurrent remission from BPD and have full time vocational engagement (Zanarini, Frankenburg, Reich & Fitzmaurice, 2010; Zanirini, Temes, Frankenburg, Bradford Reich & Fitzmaurice, 2018). In the present study, less than half of the individuals in the recovered group were engaged in a relationship or in paid work, indicating that the current sample may have a more severe presentation and experience greater psychosocial difficulties compared participants in existing longitudinal studies. Differences between the treatment context in individuals in the current sample and longitudinal studies such as The McLean Study of

Adult Development (Zanarini et al., 2018) are worth noting. Individuals in the McLean study were more functional and therefore likely to be employed than those in the current sample. This may be due to differences in capacity to pay for and access care, with the McLean sample being mainly health insured patients compared with our sample that were more reliant on stretched public services for care.

The broad recruitment strategy adopted by the study allowed for individuals to be recruited from more than one treatment service or service catchment, allowing for a wider range of views and experiences to be included in the study. However, consistent with previous research, the study adopted a retrospective approach. Difficulties in comparing individuals were encountered by researchers, as recovery is not a static process. For example, individuals in the not recovered group may have previously experienced periods in which they considered themselves as recovered and could draw on these experiences. The narratives of individuals may be subjected to some level of response bias given the significant gap between individual's age of onset, diagnosis and current age. The use of prospective longitudinal research to map recovery to obtain real time accounts may be a direction for future research. The adoption of blind data collection and analysis process may also reduce the likelihood of researcher bias. All individuals included in the sample had received a diagnosis of BPD, considered this as a turning point in their recovery, and were receiving support at the time of the interview. This indicates that the findings in this study are representative of recovery within the context of treatment. Understanding the perspectives of individuals who are underrepresented within the research literature including individuals who no longer use services, individuals in rural and remote locations, peer support workers may provide other perspectives not captured within the findings. Critical perspectives of personality disorder should also be considered (The Lancet Psychiatry, 2019; Watts, 2019), particularly where individuals who oppose the diagnosis of personality disorder.

6.7 Conclusion

This study extends the field by contrasting the experiences of individuals at either ends of the recovery continuum. The inclusion of individuals in the recovered group, provides a stronger indication of what the full recovery spectrum may constitute. The broad recruitment strategy adopted by the study allowed for individuals to be recruited from more than one treatment service or service catchment, allowing for a wider range of views and experiences to be included in the study. This model however represents recovery in the context of treatment. Therefore, it is difficult to extend these findings to individuals who seek support for BPD outside of traditional treatment services. Furthermore, future research could also focus on the experiences of men, as this has been minimally explored (Ronningstam, Keng, Ridolfi, Arbabi, & Grenyer, 2018).

CHAPTER SEVEN

OVERALL SUMMARY AND FUTURE DIRECTIONS

7.1 Preface

This final chapter aims to summarise the findings reported in Chapters Three to Six in light of the overarching research question of the thesis as outlined in Chapter One - *to empirically explore and describe the experience of recovery in BPD through the perspectives of individuals who have lived experience.* Central to the thesis were an understanding of the following: the current literature, individual goals for treatment and recovery, the definition of recovery in BPD, the effect of individual perceptions and diagnostic understandings of recovery on outcomes, and the stages and processes involved in recovery. The strengths and limitations of the research methodology are discussed, followed by recommendations for future research and implications for clinical practice.

7.2 Overview of Main Findings

The approach to the thesis was to sequentially review existing literature and empirically investigate through multiple data types the understanding of recovery. The thesis consisted of four phases of research. To identify current knowledge, Phase One systematically reviewed the empirical evidence on recovery in BPD through the perspectives of consumers, clinicians, and carers (Chapter Three). The findings from the systematic review provided the basis for the rest of the thesis. Chapter Four presented a content analysis of treatment and recovery goals important to individuals seeking treatment at a community mental health service. Chapter Five examined the role of an individual's self-perceived recovery status and diagnostic status on personal and clinical recovery outcomes. Chapter Six presented an interpretative phenomenological analysis of the stages and processes of recovery through the perspectives of individuals with lived experience. The research reported in the thesis led to several findings which furthers understanding in recovery in BPD.

7.2.1 Phase One

Differentiating the understanding of recovery through clinical and personal recovery perspectives was sought through a systematic review. Clinical recovery was over-represented in the literature, with longitudinal studies representing 16 out of 19 studies (84%). Symptomatic remission occurred in 33-99% of individuals over a 4 - 27 year follow-up period. Recurrence ranged between 10 – 36% of individuals and 7.8% of individuals retained their diagnosis. These rates indicated that BPD is a stable condition where remission is possible with the low likelihood of relapse following a period of remission.

Aggregated scores of functioning at baseline (score=42) indicated that individuals experienced serious symptoms and functional limitations. At follow-up, average aggregated

functioning scores significantly improved, signifying that individuals were functioning well, but continued to experience mild symptoms and had difficulties with vocational functioning.

Three qualitative studies described an individual's lived experiences of recovery. Perspectives fell into three broad categories: active willingness to engage in the recovery journey, improvement on clinical characteristics of BPD to facilitate change, and the conceptualisation of recovery. The views of family, carers and clinicians on recovery were not represented in the literature and may be a direction for future research.

7.2.2 Phase Two

Research in Phase Two (Chapter Four) extended knowledge by providing an in-depth understanding of the treatment and recovery goals individuals with BPD have when accessing evidence-based interventions for BPD. Major goal categories identified through a qualitative content analysis included: reducing symptoms, improving wellbeing, having better interpersonal relationships, and having a greater sense of self. These categories confirm the literature and suggest that whilst symptom remission is important for recovery, individuals desire broader psychosocial improvement (Gillard, 2015; Katsakou et al., 2012; Shepherd et al., 2017). The overlap between these goal categories and domains of psychopathology shows there is a complex relationship between clinical and personal recovery in BPD and supports the argument that they are related rather than distinct. The identification of specific goal categories indicated the areas that individuals with BPD have desire to improve on and provide researchers and clinicians an evidence-base for developing interventions which may complement existing practice.

7.2.3 Phase Three

Phase Three (Chapter Five) quantitatively examined the role of an individual's self-perceived and diagnosis status on clinical and personal recovery outcomes, and qualitatively examined how individual's defined recovery. This phase builds on Phase One and Two to identify the effect and predictors of self-perceived recovery and diagnostic status. A qualitative thematic analysis was undertaken to understand individual's definition of recovery.

Based on diagnostic status, 90% of individuals met the screening criteria for BPD. Significant differences on all clinical and personal recovery domains were identified between individuals who met criteria and those who did not. Age, relationship status and total MHI-5 score predicted the number of McLean Screening Instrument items endorsed. Findings associated with diagnostic status are in line with the clinical literature and, in light of recruitment methods, this may indicate that individuals were actively seeking support.

Significantly more individuals identified with being not recovered, according to their own recovery definitions (79.1%). No significant predictors of self-identified recovery status were identified. Individual definitions of recovery in BPD took on two conceptualisations: 1) as self-management, and 2) as not possible. Self-management was multi-faceted and consisted of an individual's desire to manage symptoms, use coping strategies, and gain a sense of comfort and acceptance of oneself.

In terms of combined self-identified recovery status and diagnostic status, the majority of individuals did not identify as recovered and met criteria for BPD (72.2%); a minority identified as recovered and did not meet criteria for BPD (3.2%). This indicates differences in how clinical and personal recovery is defined. However, individuals who self-identified with being recovered did not significantly differ on any domain of clinical or personal recovery

regardless of diagnostic status, suggesting that an individual's judgement on progress influences outcomes.

7.2.4 Phase Four

Phase Four (Chapter Six) extended on the findings from Phase Three to understand the stages and processes involved in recovery in BPD. Recovery occur across three stages: 1) being stuck, 2) receiving a diagnosis, and 3) improving experience. The last stage consisted of three domains: a) developing greater awareness of emotions and thoughts, b) strengthening sense of self, and c) understanding the perspectives of others. Four processes supported recovery and included: 1) active engagement in the recovery process, 2) hope, 3) treatment, and 4) meaningful activities and relationships. Progress through recovery occurred through the interaction between stages and processes.

As all participants were required to have a diagnosis of BPD to take part in the study, the first two stages were universally described. The average time to move from being stuck to diagnosis was approximately 16 years, indicating that there may be a knowledge gap or stigma from clinicians contributing to this delay in diagnosis. In the final stage differences were noted between individuals in the recovered and not recovered groups, with the former better able to describe the development of their sense of self and understanding of others. The stages reflected findings from qualitative studies that examined lived experience in personality disorder (Gillard et al, 2015, Katsakou et al., 2012; Shepherd et al., 2017). Whilst it is acknowledged that there are multiple pathways to recovery including recovery without using mental health services, the findings indicate that treatment was a core component with individuals on average receiving 12 years of treatment.

The complexity of recovery in BPD is highlighted in the identification of these stages and processes, where similarities between BPD psychopathology and the personal recovery domains highlighted in the CHIME framework are noted (Leamy et al., 2011). For example, both clinical and personal recovery models describe identity development. Similarly there are parallels between the concept of connection in personal recovery and the desire to improve interpersonal relationships in clinical recovery in BPD. Individual stages of recovery supported findings of other qualitative studies examining lived experience in personality disorder. Despite the identification in Phase Three that a dichotomous rating of self-identified recovery status maybe too narrow, the use of an individual's self-identified recovery status and diagnostic status as a method of grouping individuals is new and allowed for both personal definitions and clinical measures to be integrated.

7.3 Strengths and Limitations of the Research

The purpose of this section is to describe the strengths and limitations of the research more broadly. Each chapter within the thesis included a specific discussion about the strengths and limitations of the methodology utilised. While this thesis has contributed to fields of personality disorder and mental health recovery, it is not without limitations. This was the first thesis to use mixed-methods to explore the clinical and personal recovery aspects in individuals with lived experience of BPD, to describe the stages and processes of recovery, and to provide comparisons between individuals at differing stages. The mixed methods approach allowed for the exploration of different aspects associated with the recovery phenomenon.

Each empirical study (Chapters Four to Six) consisted of relatively large sample sizes, contributing to the validity and reliability of their findings. The diagnostic utility of participants was not consistent throughout the thesis. Chapter Four utilised participants

recruited from a community health service, while Chapters Five and Six recruited individuals from online sources. Within Chapters Five and Six, individuals who reported having a diagnosis of BPD were recruited and individual diagnoses were not validated with tools such as the Structured Clinical Interview – II (First, Gibbon, et al., 1997). Therefore the diagnostic status of this sample could not be confirmed.

Whilst online mediums have previously been used in research studies exploring the experience of personality disorders (Bailey & Grenyer, 2014), most individuals included in Chapter Four met diagnostic criteria for BPD using the McLean Screening Instrument (Zanarini et al., 2003a), and did not self-identify as recovered according to their own personal definition. Some sampling bias may have occurred, favouring individuals who were at early stages of their recovery journey. Yet, this method of recruitment provided the opportunity to include a wider representation of perspectives on the continuum of recovery. Despite a significantly smaller proportion of individuals who identified as recovered and no longer met criteria for BPD, comparisons between individuals could be made. Future research could include greater representation across the recovery continuum. Consistent with the broader literature in BPD, a greater proportion of women were represented in the empirical chapters, despite equal gender representation in diagnostic rates (Grant et al., 2008). Exploring men's perspectives may illuminate similarities or differences in experience, which may result in recommendations for service design or clinician training.

7.4 Implications for Clinical Practice

Policy and clinical practice guidelines have increasingly called for services to adopt a recovery-oriented approach to treatment and service delivery in Anglophone and non-Anglophone countries (Slade, 2009). Understanding an individual's lived experience can

provide a basis for understanding what is required of mental health services in order to be recovery-oriented. Four suggestions are discussed below.

First, there is a need for clinicians and other workers who engage with individuals with BPD to be aware of the clinical conceptualisation of personality disorder in general. The findings indicate a 16 year gap between an individual's perceived age of onset and age of diagnosis (see Chapter Six). Despite introducing best practice guidelines for the treatment of BPD in Anglophone countries in the past decade (Grenyer, Ng, Townsend & Rao, 2017), clinicians have been identified to have a knowledge gap and negative attitudes towards individuals with BPD (Cleary, Siegfried & Walter, 2002; Lam, Salkovskis & Hogg, 2016). Whilst clinician attitudes have improved over the past 15 years (Day, Hunt, Cortis-Jones, & Grenyer, 2018), the findings indicate that clinicians and other workers need further upskilling to increase understanding and redress negative attitudes.

Second, awareness and understanding of how to deliver recovery-oriented person-centred services is required. What is clear from the findings is that individual's recovery in BPD incorporates both the self-management of symptoms and the achievement of personally meaningful goals, where an individual's perception of recovery impacts their clinical and personal recovery outcomes. Additionally, the low proportion of individuals identifying with being recovered in accordance with their own definitions in Phase Three (Chapter Four) suggest that clinical understandings of BPD may not sufficiently encapsulate an individual's experience. One suggested method may be having ongoing discussions with individuals to identify their own definition and goals for recovery, and monitoring changes or progress made. The dialogue between the individual and clinician through motivational interviewing can lead to tailored treatment that is person-centred. Engaging in meaningful activities and relationships can promote progression through recovery stages and is supported by wider

research evidence (Leamy et al., 2012). Encouragement and support to engage in activities, vocation, and relationships, should be provided in conjunction with treatment, rather than firstly focusing on symptomatic remission. This is supported by findings in Phase Four (Chapter Six; Ng, Townsend, Miller, Jewell & Grenyer, 2019) indicating that these elements support recovery.

Third, while the role of clinicians in supporting recovery is crucial, a consideration of wider systemic influences should be made. The organisational commitment of the wider mental health system in providing recovery-oriented services can influence delivery, accordingly, having a recovery vision, appropriate workplace support structures, quality improvement, clear care pathways, and workforce planning is crucial (Le Boutillier et al., 2011). Although an organisational perspective was not a core component of the current thesis, individual responses indicate that people's experiences of organisations and iatrogenic harms can hinder recovery (for example, negative experiences of diagnosis or help seeking). Promoting a culture of recovery within systems may support clinicians to provide better services, while reducing their therapeutic nihilism. It may also increase hope within individuals.

Fourth, the findings suggest that there are opportunities to incorporate psychosocial and adjunct interventions into evidence-based interventions for BPD. Recovery-oriented interventions integrating the lived experience of individuals (such as peer support, and recovery colleges) have emerged within mental health systems internationally (Slade, 2009) and empirical evidence has supported their efficacy (Pitt et al., 2013; Hall et al., 2018). Similarly, developing interventions to target specific population groups may be appropriate to support individuals. For example, the development of a parenting intervention for parents with personality disorder has been identified as an acceptable treatment by clinicians (Gray,

Townsend, Bourke & Grenyer, 2018; McCarthy et al., 2016). The provision of differing types of treatment provides individuals with choice and can promote their self-determination.

The personality disorder field is currently in transition to a dimensional approach to understanding personality disorder (Grenyer, 2017). The dimensional approach, in accordance to the ICD-11 classification of personality disorders focuses on an individual's personality functioning and traits (Bach & First, 2018). Three levels of severity (mild, moderate, and severe personality disorder) and the specification of trait domains (negative affectivity, detachment, disinhibition, dissociality, and anankastia) an individual may be exhibiting (Bach & First, 2018). The shift in approach represents theories from the psychodynamic traditions and personality traits approaches to understanding personality disorder. Knowledge generated through sociological or humanities approaches have largely been not considered in the development of the dimensional approach. The findings of this thesis indicate that the social realm of an individual's life (e.g. relationships, work and employment, meaningful activities) and perspectives may contribute to recovery. The integration of the consumer voice to traditional psychodynamic and personality trait theories currently used in the development of the dimensional model, may lead to a more holistic approach to the development of the personality disorder diagnostic criteria.

7.5 Future Research Directions

Consistent with current research in mental health recovery, the research employed a cross-sectional methodology. However, as identified in Chapter Six, recovery in BPD is an ongoing and a fluctuating process, which cross-sectional methods may not fully encapsulate. The use of ecological momentary assessment techniques to prospectively explore the experience of recovery may lead to a more nuanced understanding of real-time changes and reduce memory bias. The development of identity has been established by the clinical literature and

individuals with lived experience as an important component of recovery. Yet, limited investigation of the differences of what constitutes identity from a clinical viewpoint and personal identity has been conducted within the context of BPD and may be a topic for future research.

While there is emphasis on integrating the perspectives of individuals with lived experience into treatment, the recovery model also acknowledges the importance of the knowledge of carers and clinicians (Slade, 2009). Chapter Three identified that no studies to date have been conducted to examine the perspectives of carers and clinicians in the context of recovery in BPD exist. The multifaceted nature of recovery indicates including perspectives of carers and clinicians may be crucial in developing holistic care. Carers of individuals with personality disorder have been demonstrated to have higher levels of burden and mental distress (Bailey & Grenyer, 2014). Whilst psychoeducation groups are effective in reducing burden (Grenyer et al., 2018), exploring the perspectives of families and carers on recovery may provide insight into their experiences. Contrasting the perspectives of carers and individuals with lived experience may lead to recommendations for rectifying differing perspectives. This coincides with criticisms of the personal recovery model, to incorporate relational aspects (Price-Robertson et al., 2016).

Societal contributions to mental health have been documented within the literature (Tew et al., 2011). Whilst the effect of society on recovery extended beyond the scope of the thesis, societal experiences can significantly affect an individual's ability to recover. For example, reports on housing in Australia indicate that mental health and homelessness can have a compounding bi-directional effect on each other (Brackertz, Wilkinson & Davison, 2018). While this is not specific to individuals with BPD, societal circumstances can have an effect on an individual's ability to self-manage their mental health condition, identity and to engage

in meaningful activities. Greater consideration of the societal impact on mental health is required to gain a holistic view of how they affect the outcomes of individuals.

7.6 Conclusion

The research presented in this thesis empirically explored and described the experience of recovery in BPD through the perspectives of individuals with lived experience. Based on findings from four phases of research, recovery in BPD is an ongoing and fluctuating journey incorporating the reduction of symptoms and personally meaningful psychosocial goals. Definitions of recovery are unique to individuals and may change over time. Therefore they should be monitored as they can impact clinical and personal recovery outcomes. A greater focus on individual motivation, hope, engagement in activities and relationship, and treatment is required in order to assist progression in recovery.

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LIST OF APPENDICIES

Appendix P: Additional illustrative quotes from Phase Four

APPENDIX A: Right to Reproduce Published Manuscript Presented as Chapter Four

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Wolters Kluwer

Title: What Do Individuals With Borderline Personality Disorder Want From Treatment? A Study of Self-generated Treatment and Recovery Goals

Author: FIONA NG, PHOEBE CARTER, MARIANNE BOURKE, et al

Publication: Journal of Psychiatric Practice

Publisher: Wolters Kluwer Health, Inc.

Date: Mar 1, 2019

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APPENDIX B: Contribution of Co-Authors

Chapter Three

Ng, F.Y.Y., Bourke, M.E., & Grenyer, B.F.S. (2016). Recovery from Borderline Personality Disorder: A Systematic Review of the Perspectives of Consumers, Clinicians, Family and Carers. *Plos One, 11*(8), e0160515. doi: 10.1371/journal.pone.0160515.

FYYN designed the study, conducted systematic review searches, curated the data, conducted the formal analysis, and drafted the manuscript. MEB and BFSG contributed to the design of the study and the interpretation of the data. All authors contributed to the final version of the manuscript.

Chapter Four

Ng, F.Y.Y., Carter, P.E., Bourke, M.E., & Grenyer, B.F.S. (2019). What Do Individuals with Borderline Personality Disorder Want From Treatment? A Study of Self-Generated Treatment and Recovery Goals. *Journal of Psychiatric Practice. 25*(2), 148-155. doi: 10.1097/PRA.0000000000000369

FYYN designed the study, conducted the formal data analysis and interpretation, and wrote the first draft of the manuscript. MEB and BFSG contributed to the design and interpretation of the findings. PC was the secondary coder for qualitative data analysis. BFSG provided the archival data. All authors read and approved the final version of the manuscript.

Chapter Five

> **Ng, F.Y.Y.,** Millet, S., Townsend, M.L., & Grenyer, B.F.S. Clinical and Personal Recovery in Borderline Personality Disorder: The Role of Self-Identified Recovery Status and Diagnostic status on Outcomes. Manuscript under review at Social Psychiatry and Psychiatric Epidemiology.

FYYN designed the study, recruited participants, collected survey data, conducted the statistical data analysis, coded the qualitative data, interpreted the findings, and wrote the first draft of the manuscript. MLT was the secondary coder for the qualitative data analysis and contributed to the interpretation of the results. SM contributed to the statistical analysis and the interpretation of the findings. BFSG contributed to the design of the study and the interpretation of the results. All authors read and approved the final version of the manuscript.

Chapter Six

> **Ng, F.Y.Y.,** Townsend, M.L., Miller, C.E., Jewell, M, & Grenyer, B.F.S. (2019). The lived experience of recovery in borderline personality disorder: A qualitative study. *Borderline Personality Disorder and Emotion Dysregulation. 6*(10), 1-9. doi: 10.1186/s40479-019-0107-2

FYYN designed the study, recruited participants, conducted all participant interviews, conducted the formal data analysis, and wrote the first draft of the manuscript. MLT contributed to the interpretation of the results. CM was the secondary coder for qualitative data analysis. MJ contributed to the interpretation of the results. BFSG contributed to the design of the study and interpretation of the results. All authors read and approved the final version of the manuscript.

APPENDIX C: PROSPERO Registration

PROSPERO
International prospective register of systematic reviews

NHS National Institute for Health Research

Recovery from borderline personality disorder: a systematic review of the experiences of consumers, clinicians and family and carers

Fiona Ng, Brin Grenyer

Citation

Fiona Ng, Brin Grenyer. Recovery from borderline personality disorder: a systematic review of the experiences of consumers, clinicians and family and carers. PROSPERO 2015 CRD42015019838 Available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42015019838

Review question

How do consumers, clinicians and family and carers understand and experience recovery from Borderline Personality Disorder (BPD)?

Searches

Databases searched:
1) PsycINFO
2) Web of Science
3) Scopus
4) Psychological and Behavioral Collection
5) PubMed
Inclusion Criteria
1) Contains the perspectives of consumers with BPD
2) Contains the perspectives of clinicians who work with consumers with BPD
3) Contains the perspectives of family and carers of consumers with BPD
4) Main focus of research study is on Borderline Personality Disorder (comparison groups may be present in the study, however the population at interest must be BPD)
5) Articles focused on examining the recovery process in regards to remission of symptoms or consumer experiences of recovery
6) Participants are from community or inpatient settings (not forensic settings)
7) Qualitative or longitudinal methodology
Note: [(1) AND/OR (2) AND/OR (3)] AND [(4) AND (5) AND (6) AND (7)].
Limits
(1) English Language
(2) Human

Search strategy

http://www.crd.york.ac.uk/PROSPEROFILES/19838_STRATEGY_20150324.pdf

Types of study to be included

Only studies that have adopted a qualitative methodology or longitudinal study method will be included in the review with a focus on recovery.

Condition or domain being studied

Borderline Personality Disorder (BPD) has historically been stigmatised as an untreatable disorder which is estimated to affect 1% of the Australian population (Jackson & Burgess, 2000). Recent developments in the literature have reported on the increasing rates of remission, which has driven the notion that recovery from BPD is possible. However, a number of definitions of recovery have been posited in the literature with the clearest divide separating clinical and personal aspects of recovery (Slade, 2009). Although longitudinal studies have examined rates of remission, relapse and functioning levels of consumers with BPD, limited knowledge surrounding the consumer experience of recovery from BPD and their goals for recovery have been examined in the literature. With the international push towards recovery-oriented mental health services that are tailored to individual consumer needs, greater understanding of the experiences and connotations of recovery through the perspectives of consumers is required. Moreover, with the growing emphasis on the role support networks (including family and carers and health professionals) in the recovery process, there is limited understanding of what roles of these groups have and their understanding of these groups in the

recovery process of consumers from BPD.

Participants/population

Participants in this review will include:
1) Consumers diagnosed with BPD
2) Clinicians who provide clinical services to consumers with BPD
3) Family and carers of consumers with BPD

Intervention(s), exposure(s)

The inclusion criteria for the review is broad such that perspectives of consumers (criterion 1), clinicians (criterion 2) or family and carers (criterion 3) separately or within the same framework will be included in the review. However, the topic of examination must be focused on Borderline Personality Disorder (criterion 4), about the recovery process (criterion 5), conducted within a community or inpatient setting (criterion 6) and use a longitudinal or qualitative methodology (criterion 7).
Studies will be excluded from the review if they are:
- Intervention or treatment studies
- Not published in English
- Include participants from forensic settings

Comparator(s)/control

No comparison group

Context

Only studies completed within a community or inpatient hospital setting will be included in the review. Studies where consumers with BPD are based in forensic settings will be excluded.

Main outcome(s)

Primary outcomes of interest are the global outcomes associated with BPD. In particular, the experiences and perceptions of consumers, clinicians and family and carers on the recovery process from BPD. The rate and time to attainment/loss of symptomatic remission and relapse will also be examined.

Additional outcome(s)

None

Data extraction (selection and coding)

Articles will be identified through a number of methods including searching electronic databases, manually scanning reference lists of included articles and obtaining articles known to researchers.
Firstly, an electronic database search will be conducted as per the strategy listed above. The title and abstracts of articles identified will be screened independently by one researcher. Potential articles for inclusion will be obtained in full and independently assessed by two researchers. Secondly, manual reference list searches of articles included for review will be undertaken by one researcher to identify additional resources. This will be completed twice – firstly on the articles identified from the electronic search and secondly on articles identified from the first reference list search. Finally, articles known to the researchers which comply with the inclusion criteria will be included in the review (including recently published articles). Disagreements between the review team will be discussed and resolved via consensus.
Preliminary data extraction table will include information about; study type, location of study, sample, aims, inclusion and exclusion criteria, data collection method and measures used, findings and limitations.

Risk of bias (quality) assessment

Risk of bias will be reduced through searching for articles through a variety of sources – including electronic database searching, reference list searching and articles known to researchers.
Qualitative and quantitative articles included for review will be assessed for quality using different tools which tailor to the specific methods. Quantitative articles will be assessed using an adapted version of Luppino and colleagues (2010) study. The assessment tool assesses domains including the study population, follow up, the inclusion of baseline and follow up information and the measurement tools used. Each article is rated either a + (score =1), - (score = 0) or ? (score =0). Articles were considered good quality when scored =60% of the maximum possible score. Studies scoring < 60% will be excluded from the review.
Quality assessment of qualitative articles involves examining the credibility and rigor of individual articles.

Included qualitative articles will be assessed for quality using the guidelines developed by Kuper, Lingard and Levinson (2008). As noted by Kuper and colleagues, the assessment of quality in qualitative research requires reflection on the rigor and credibility of findings. The guideline consists of six questions that examines areas including; sample, data collection, data analysis, transferability of results ethical considerations (including reflexivity) and overall coherence of study. Included qualitative studies will also be categorised in terms of Daly and colleagues' (2007) hierarchy of evidence for qualitative health research. This hierarchy indicates the strength of qualitative studies and consists of four levels; single case studies (weakest), descriptive studies, conceptual studies and generalisable studies (strongest).

Strategy for data synthesis
Thematic synthesis of the findings from studies included in the review will be completed. Data will be extracted and tabulated under the following headings; source, location, sample, aims, inclusion and/or exclusion criteria, data collection and analysis method used, findings and limitations, in order to identify commonalities and differences between the studies.

Analysis of subgroups or subsets
None planned

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Ng, F. Y. Y., Bourke, M.E., & Grenyer, B.F.S. (2016). Recovery from Borderline Personality Disorder: A Systematic Review of the Perspectives of Consumers, Clinicians, Family and Carers. Plos One, 11(8), e0160515. doi: 10.1371/journal.pone.0160515

http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0160515

Subject index terms status

Subject indexing assigned by CRD

Subject index terms
Biological Phenomena; Borderline Personality Disorder; Caregivers; Humans; Physiological Phenomena

Date of registration in PROSPERO
24 April 2015

Date of publication of this version
11 August 2016

Revision note for this version
The review has been completed and published.

Details of any existing review of the same topic by the same authors

Stage of review at time of this submission
The review has not started

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	Yes	Yes
Risk of bias (quality) assessment	Yes	Yes
Data analysis	Yes	Yes

Revision note
The review has been completed and published.

Versions
24 April 2015
28 April 2015
11 August 2016

APPENDIX D: Detailed Search Strategy for Phase One

Systematic Review Protocol

Recovery from Borderline Personality Disorder – A Systematic Review of the Experiences of Consumers, Clinicians and Family and Carers.

Fiona Ng (PhD Candidate)

Professor Brin Grenyer

2015

Development of the Research Question

The research question was formulated through using the PICO acronym.

Population	Consumers with a diagnosis of BPD
	Clinicians who provide clinical services to consumers with BPD
	Family and carers of consumers with BPD
Intervention/Exposure	Borderline Personality Disorder
Comparison	No comparison group
Outcomes	Recovery
	Reduction of symptoms
	Experiences and perceptions of recovery
Study Designs	Qualitative and longitudinal methodologies

Research question:

How do consumers, clinicians and family and carers understand and experience recovery from Borderline Personality Disorder over time?

Search Strategy

The process for selecting articles for inclusion was adopted from the Cochrane Handbook for Systematic Reviews of Interventions (http://handbook.cochrane.org/) and Sutton et al (1998).

Electronic Databases:

Both the Cochrane Collaboration and Sutton and colleagues suggest a systematic search of electronic databases to maximise the number of articles found for screening.

Five electronic databases were chosen based on their scope and relevance to the research question. These included;

- PsychINFO
- Psychological and Behavioural Collection
- PubMed
- Scopus
- Web of Science

The same search strategy was implemented in each database. Results were limited to the English language and research conducted with humans. No limit on date of publication was applied as it was expected that a limited number of records would be identified.

Search Term Strategy

> [(Consumer OR Client OR Patient OR Service User) AND/OR (Clinician OR Therapist) AND/OR (Family OR Carer OR Significant Other)] AND [(Borderline Personality Disorder OR BPD) AND (Qualitative OR Longitudinal) AND (Remission OR Recovery OR Hope OR Psychotherapy OR Therapy OR Client Cent* OR Resilience OR Social Support OR Wellbeing OR Rehabilitation OR Meaning OR Social Inclusion)].

Scanning reference lists (footnote chasing):

Sutton and colleagues (1998) suggest the manual searching of reference lists of included articles to further identify articles for potential inclusion. This method of searching will be completed twice, firstly on articles identified through the electronic database search and secondly on articles identified from the first manual reference list search.

Known articles:

Articles known to the researchers that have not been identified through the electronic or manual reference list search and may be suitable for inclusion will be obtained including recently published articles.

All articles found through the electronic database search, manual searching of reference lists and articles known to the researchers will be assessed through the inclusion criteria (stated on page 5).

Study Selection

The process of selecting studies for inclusion will be as follows:

- One researcher will conduct the search and identify potential articles for inclusion in the review
- Full text of potential articles will be obtained in full and assessed in line with the inclusion criteria. Included articles will be checked by the second researcher who is an expert in personality disorders
- Disagreements about inclusion will be resolved by consensus

Inclusion Criteria:

1) Contains the perspectives of consumers with BPD

2) Contains the perspectives of clinicians who work with consumers with BPD

3) Contains the perspectives of family and carers of consumers with BPD

4) Main focus of research study is on BPD (comparison groups may be present in the study, however the population at interest must be BPD)

5) Articles focused on examining the recovery process in regards to remission of symptoms or consumer experiences of recovery

6) Participants are from community or inpatient settings (not forensic settings)

7) Qualitative or longitudinal methodology

Note: For articles to be included in the review criteria 1 AND/OR 2 AND/OR 3 AND all criteria from 4 to 7 need to be fulfilled.

Methods of Data Extraction

Assessing quality and risk of bias

Risk of bias will be reduced through searching for articles through a variety of sources – including electronic database searching, manual searching of reference lists and articles known to researchers.

Quantitative Research

Quantitative articles will be assessed using an adapted version of Luppino and colleagues (2010) study. The assessment tool assesses domains including the study population, follow up, the inclusion of baseline and follow up information, the measurements and analysis tools used. Each article is rated either a + (score =1), - (score = 0) or ? (score =0). Articles were considered good quality when scored ≥60% of the maximum possible score. Studies scoring < 60% will be excluded from the review.

Qualitative Research

Qualitative articles identified to meet the inclusion criteria will be assessed for quality using the guidelines developed by Kuper, Lingard and Levinson (2008). As noted by Kuper and colleagues, the assessment of quality in qualitative research requires reflection on the rigor and credibility of findings. The guideline consists of six questions that examines areas including; sample, data collection, data analysis, transferability of results ethical considerations (including reflexivity) and overall coherence of study. Included qualitative studies will also be categorised in terms of Daly and colleagues' (2007) hierarchy of evidence for qualitative health research. This hierarchy indicates the strength of qualitative studies for use in health practice and policy. The hierarchy consists of four levels; single case studies (weakest), descriptive studies, conceptual studies and generalisable studies (strongest).

Data Extraction Table

The preliminary data extraction table may change in order to ensure all relevant information is included

Source	Study type	Location	Sample	Aims	Inclusion and/or exclusion criteria	Data Collection and Analysis Method	Findings	Limitations

Reporting the Review

The reporting of the systematic review will follow the PRISMA guidelines as proposed by Liberatti and colleagues (2009).

Title: The title of the review will indicate that it is a systematic review

Abstract: The abstract will include information about the background, objectives, databases searched, the inclusion criteria, description of the exposure and participants, how the included studies were appraised and synthesised and include a brief summary of the results, limitations and clinical implications of the findings.

Introduction: Will provide a rationale and objectives of the systematic review.

Methods: The methods section will provide information about the registration of the review, the eligibility criteria for inclusion in the review, sources of data collection, the full search strategy for each database including limits applied, the inclusion and exclusion criteria, how data was extracted from the included studies, how risk and bias was assessed in the included studies.

Results: Will provide a description of studies and participant characteristics from the included studies and the main findings from the review. A flow chart will also be provided to depict the process of article inclusion and exclusion.

Discussion: Will provide a summary of the main findings, limitations, conclusion and future research directions.

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APPENDIX E: Ethics Approval for Phase Three and Four

Dear Professor Grenyer,

I am pleased to advise that the amendment request submitted on 02/12/2016 to the application detailed below has been **approved.**

Ethics Number:	2016/215
Amendment Approval Date:	06/12/2016
Expiry Date:	18/07/2017
Project Title:	Journeys to Recovery: The lived experience of Borderline Personality Disorder
Researcher/s:	Bourke Marianne; Ng Fiona; Grenyer Brin
Documents Approved:	Online Survey V3 - 30/11/2016 Consent Form Telephone Interview V3 - 30/11/2016 Participant Information Sheet and Consent for Online V1 - 30/11/2016 Phase 2 Interview Schedule recovered V3 - 30/11/2016 Phase 2 Interview Schedule not recovered V1 - 30/11/2016 Blog Social Media Recruitment V1 - 30/11/2016 Participant Information Sheet Telephone Interview V3 - 30/11/2016
Amendments Approved:	Changes to the inclusion criteria, methodology and protocol as outlined in the amendment coversheet

The HREC has reviewed the research proposal for compliance with the *National Statement on Ethical Conduct in Human Research* and approval of this project is conditional upon your continuing compliance with this document. Compliance is monitored through progress reports; the HREC may also undertake physical monitoring of research.

Please remember that in addition to submitting proposed changes to the project to the HREC prior to implementing them the HREC requires:

- Immediate report of serious or unexpected adverse effects on participants.
- Immediate report of unforeseen events that might affect the continued acceptability of the project.
- The submission of an annual progress report and a final report on completion of your project.

If you have any queries regarding the HREC review process or your ongoing approval please contact the Ethics Unit on 4221 3386 or email rso-ethics@uow.edu.au.

Yours sincerely,

Colin Thomson

Professor Colin Thomson,
Chair, UOW & ISLHD Health and Medical Human Research Ethics Committee

The University of Wollongong and Illawarra and Shoalhaven Local Health District Health and Medical HREC is constituted and functions in accordance with the NHMRC National Statement on Ethical Conduct in Human Research. The processes used by this HREC to review multi-centre research proposals have been certified by the National Health and Medical Research Council.

APPENDIX F: Online Participant Information Sheet and Consent Form for Phases Three and Four

PROJECT TITLE: Journeys to Recovery: The Lived Experience of Borderline Personality Disorder

RESEARCHER: Fiona Ng, BHlthSci(Hons), PhD (Psychology) Candidate, School of Psychology and Illawarra Health and Medical Research Institute, University of Wollongong, Australia; Phone: +61 2 4239 2152. Email: fionan@uow.edu.au

SUPERVISORS: Professor Brin Grenyer, School of Psychology, Illawarra Health and Medical Research Institute, University of Wollongong, Australia; Phone: +41 2 4221 3474, Email: grenyer@uow.edu.au

Dr Marianne Bourke, School of Psychology and Illawarra Health and Medical Research Institute, University of Wollongong, Australia; Email: mbourke@uow.edu.au

PURPOSE OF THE RESEARCH:

This research project aims to understand the perspectives and experiences of recovery in individuals with a lived experience of Borderline Personality Disorder. This study is being conducted by Fiona Ng as part of the Doctor of Philosophy (Psychology) program, under the supervision of Professor Brin Grenyer of the School of Psychology, University of Wollongong.

WHAT DOES THE STUDY INVOLVE?

The Journeys to Recovery is a two phase study where participation involves completing an online interview and an optional telephone interview about your experiences with Borderline Personality Disorder and your recovery journey. All individuals with a diagnosis of Borderline Personality Disorder are invited to participate in the study.

In the first phase, the online questionnaire will ask about my quality of life, symptoms, treatment history, and my views about the term recovery. At the end of the questionnaire I will be invited to leave your contact details if I am interested in participating in the second phase of the study, a telephone interview. The telephone interview is an optional component of the study where I will be asked about my experiences with Borderline Personality Disorder, treatment, and what has helped me in the past and present.

POSSIBLE RISKS AND BENEFITS:

I have been given information about the research aims and have been advised that should I want further information I am able to discuss this with the research, Fiona Ng. I understand that if I decide to participate, I will be asked to complete a survey that should take approximately 30 minutes to complete. This survey will ask questions about my quality of

life, symptom experience, treatment history, and my views on about the term recovery (for example ‘how do I define the term recovery from Borderline Personality Disorder?’).

I understand that I am also invited to participate in an optional telephone interview (of approximately 45 minutes) that may be audio recorded. I understand that audio recorded interviews will be transcribed and the audio recording then destroyed. I understand I will be asked questions such as ‘can you describe your life at the present moment?’ I understand that participation in this research is voluntary, includes no immediate benefit to myself, however may provide the opportunity to voice my story and experiences with BPD and recovery. I may refuse to participate or withdraw my data at any time without consequence. If I wish to withdraw from the study whilst completing the online survey, I simply have to exit the survey or if I wish to withdraw from the telephone interview, I simply have to advise the researcher of my decision.

I understand that all information provided will be kept strictly confidential. The data collected will be used for the purpose of journal publications, conference presentations, a doctoral research thesis and to help the community understand the recovery processes involved in Borderline Personality Disorder. Summary information only will be included, therefore no individual will be identifiable in the reporting of results.

CONTACTS:

If I have any questions about this research, I can contact Fiona Ng or Professor Brin Grenyer. I understand that answering personal questions can sometimes be distressing and that residents in Australia can contact Lifeline on tel: 13 11 14 for a free counselling service 24 hours per day, 7 days per week if participating in the study is distressing. If outside Australia, please contact your local doctor or hospital health service.

ETHICS REVIEW:

I understand that the ethical aspects of the study have been approved by the Social Sciences Human Research Ethics Committee at the University of Wollongong. If I have concerns or complaints regarding the way this research has been conducted, I can contact the University of Wollongong Ethics Officer on +61 2 4112 3386 or email rso-ethics@uow.edu.au

CONSENT:

If you decide to participate in this study, please complete the following questions. By clicking ‘I ACCEPT’ below and answering these questions you are indicating that you agree to participate in this study. If you do not wish to participate, simply close this link.

By pressing one of the buttons below I am indicating my agreement, or otherwise, to participate in this research

☐ I accept

☐ I do not wish to proceed

Once you have completed the survey you will be asked if you wish to be involved in a follow-up telephone interview. Participation in the telephone interview is voluntary and there will be no consequences should you decline to be contacted.

APPENDIX G: Online Survey used in Phase Three

Screener

1. Have you previously been given a diagnosis of Borderline Personality Disorder?

☐ Yes
☐ No

Yes (1)	No (0)
Participant will continue onto the next question	The following message will appear: *'Thank you for your interest in this study. Unfortunately you are not eligible for participation. Should you require any further information, please contact the researchers as outlined in the participant information sheet.'*

2. Have you been given any of the following diagnoses by a health professional? (*Tick all that apply)*

☐ Anxiety Disorder
☐ Depressive Disorder
☐ Bipolar Disorder
☐ Eating Disorder
☐ Post-Traumatic Stress Disorder
☐ Psychosis
☐ Substance Abuse
☐ Other Personality Disorder
☐ Other _____
☐ None

Recovery Status

3. How do you define 'recovery' from Borderline Personality Disorder?

_____

4. According to your own definition of recovery, do you now consider yourself as 'recovered'?

☐ Yes
☐ No

5. How old were you when you were diagnosed with Borderline Personality Disorder?

_____years

6. To the best of your knowledge, how old were you when you first noticed your difficulties with Borderline Personality Disorder?

_____years

Treatment History and Service Utilisation

7. Are you currently receiving psychological treatment for Borderline Personality Disorder?

☐ Yes
☐ No

8. Which psychological treatments have you received (current and in the past) for Borderline Personality Disorder? (Tick all that apply)

☐ Dialectical Behavioural Therapy (DBT)
☐ Mentalisation Based Therapy (MBT)
☐ Transference Focused Psychotherapy (TFP)
☐ Schema Focused Psychotherapy (SFP)
☐ Cognitive Behavioural Therapy (CBT)
☐ Interpersonal Therapy (IPT)
☐ Dynamic Interpersonal Therapy (DIT)
☐ Psychodynamic Psychotherapy
☐ Conversation Model (CM)
☐ Cognitive Analytic Therapy (CAT)
☐ Psychoanalysis
☐ Mindfulness Skills
☐ Family Therapy
☐ Counselling and Support
☐ Other psychological therapy, *please describe:* _____
☐ No Treatment Received

9. How long have you received psychological treatment? _____ years

10. Which non-clinical supports have you engaged in (current and in the past) for Borderline Personality Disorder? (Tick all that apply)

☐ Recovery College
☐ Clubhouse
☐ Peer Support
☐ Self-help
☐ Other psychosocial supports, *please describe:*_____
☐ No non-clinical supports received

11. Which pharmacological therapies have you received (current and in the past)? (Tick all that apply)

☐ No Pharmacological Treatment Received
☐ Fluoxetine (Prozac, Sarafem, Adofen)
☐ Paroxetine (Paxil, Seroxat, Pexeva, Brisdelle, Rexetin)
☐ Citalopram (Celexa, Cipramil)
☐ Escitalopram (Lexapro, Cipralex)
☐ Sertraline (Zoloft)
☐ Duloxetine (Cymbalta)
☐ Venlafaxine (Effexor, Effexor XR, Lanvexin, Viepax, Trevilor)
☐ Bupropion (Wellbutrin, Zyban, Elontril)
☐ Mirtazapine (Remeron)
☐ Isocarboxazid (Marplan)
☐ Phenelzine (Nardil, Nardelzine)
☐ Tranylcypromine (Parnate)

☐ Chlorpromazine (Thorazine, Largactil)
☐ Haloperidol (Hadol)
☐ Perphenazine (Trilafon)
☐ Thioridazine (Melleril, Mellaril)
☐ Thiothixene (Navane)
☐ Flupenthixol (Fluanxol, Depixol)
☐ Trifluoperazine (Stelazine, Eskazinyl, Eskazine, Jatroneural, Modalina, Terfluzine, Triftazin)
☐ Aripiprazole (Abilify)
☐ Clozapine (Clozaril, FazaClo, Versacloz)
☐ Olanzapine (Zyprexa)

☐ Paliperidone (Invega)
☐ Quetiapine (Seroquel)
☐ Risperidone (Risperdal)
☐ Zotepine (Losizopilon, Lodopin, Setous)
☐ Ziprasidone (Geodon, Zeldox, Zipwell)

☐ Alprazolam (Xanax)
☐ Chlordiazepoxide (Librium)
☐ Clonazepam (Klonopin)
☐ Diazepam (Valium)
☐ Lorazepam (Ativan, Tavor, Temesta)
☐ Nitrazepam (Mogadon, Alodorm, Apodorm, Arem, Insoma, Paxadorm, Remnos)
☐ Temazepam (Restoril, Normison, Nortem)
☐ Eszopiclone (Lunesta)
☐ Zaleplon (Sonata, Starnoc, Andante)
☐ Zolpidem (Ambien, Stilnox)
☐ Zopiclone (Imovan, Zimovane)

☐ Lithium (Carbolith)
☐ Carbamazepine (Tegretol)
☐ Oxcarbazepine (Trileptal)
☐ Valproic acid (Depakote, Convulex, Epilim, Stavzor, Vilapro)
☐ Lamotrigine (Lamictal)
☐ Gabapentin (Neurontin)
☐ Pregabalin (Lyrica)
☐ Topiramate (Topamax)

☐ Methylphenidate (Ritalin, Concerta)
☐ Dexmethylphenidate (Focalin, Attenade)
☐ Mixed amphetamine salts (Adderall)
☐ Dextroamphetamine (Dexedrine, Metamina, Attentin, Zenzedi, Procentra, Amfexa)
☐ Lisdexamfetamine (Vyvanse, Tyvense, Elvanse, Venvanse)
☐ Methamphetamine (Desoxyn)
☐ Other Pharmacological Treatment, *please describe:*_____

12. In the last 12 months have you been seen as an inpatient for a psychological/emotional problem?

☐ Yes
☐ No

13. If so, **how many** times in the past 12 months have you been seen as an inpatient for a psychological/emotional problem?

_____

14. Have you received any other types of treatment of Borderline Personality Disorder?

_____

BPD Screener

	None of the time	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**
15. Have you had at least two problems with **impulsivity** (e.g. eating binges and spending sprees, drinking too much and verbal outbursts?)	1	2	3	4	5	6
16. Have you been extremely **moody**?	1	2	3	4	5	6
17. Have you felt very **angry** a lot of the time? How about often acted in an angry or sarcastic manner?	1	2	3	4	5	6
18. Have you often been **distrustful** of other people?	1	2	3	4	5	6

19. Have you frequently felt **unreal** or as if things around you were unusual?

Never happens to me **Always happens to me**										
0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%

20. Have you frequently found you **cannot remember** things, such as suddenly realising you don't remember what happened on a car trip, or listening to someone talk and suddenly realising you did no hear part of what was said?

Never happens to me **Always happens to me**										
0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%

	None of the time	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**
21. Have you chronically felt **empty**?	1	2	3	4	5	6
22. Have you often felt that you had no idea of who you are or that you have **no identity**?	1	2	3	4	5	6
23. Have you made desperate efforts to avoid feeling abandoned or being **abandoned** (e.g. repeatedly called someone to reassure yourself that he or she still cared, begged them not to leave you, clung to them physically?)	1	2	3	4	5	6
24. Have any of your closes **relationships** been troubled by a lot of arguments or repeated breakups?	1	2	3	4	5	6

Mental Health Inventory - 5

In the past two weeks, how much of the time:

	None of the time	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**
25. Have you been a very **nervous** person?	1	2	3	4	5	6
26. Have you felt so **down in the dumps** that nothing could cheer you up?	1	2	3	4	5	6

27. Have felt **calm** and peaceful?	6	5	4	3	2	1
28. Have you felt **downhearted** and blue?	1	2	3	4	5	6
29. Have you been a **happy** person?	6	5	4	3	2	1

Quality of Life

30. How would you rate your **quality of life?**

Very Bad		**Bad**		**Moderate**			**Good**		**Very Good**	
0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%

31. How **satisfied** are you with your health?

Very Bad		**Bad**		**Moderate**			**Good**		**Very Good**	
0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%

32. How do you rate your **overall health?**

Very Bad		**Bad**		**Moderate**			**Good**		**Very Good**	
0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%

33. Overall, how much did you difficulties **interfere** with your life?

Very Bad		**Bad**		**Moderate**			**Good**		**Very Good**	
0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%

Recovery Assessment Scale – Domains and Stages

Doing Things I Value				
	Untrue	**A bit true**	**Mostly true**	**Completely true**
34. It is important to have fun	1	2	3	4
35. It is important to have healthy habits	1	2	3	4
36. I do things that are meaningful to me	1	2	3	4
37. I continue to have new interests	1	2	3	4
38. I do things that are valuable and helpful to others	1	2	3	4
39. I do things that give me a feeling of great pleasure	1	2	3	4
Looking Forward				
	Untrue	**A bit true**	**Mostly true**	**Completely true**
40. I can handle it if I get unwell again	1	2	3	4
41. I can help myself become better	1	2	3	4
42. I have the desire to succeed	1	2	3	4
43. I have goals in life that I want to reach	1	2	3	4
44. I believe that I can reach my current personal goals	1	2	3	4
45. I can handle what happens in my life	1	2	3	4
46. I like myself	1	2	3	4
47. I have a purpose in life	1	2	3	4
48. If people really knew me they would like me	1	2	3	4

49. If I keep trying, I will continue to get better	1	2	3	4
50. I have an idea of who I want to become	1	2	3	4
51. Something good will eventually happen	1	2	3	4
52. I am the person most responsible for my own improvement	1	2	3	4
53. I am hopeful about my own future	1	2	3	4
54. I know when to ask for help	1	2	3	4
Mastering My Illness				
	Untrue	**A bit true**	**Mostly true**	**Completely true**
55. I can identify the early warning signs of becoming unwell	1	2	3	4
56. I have my own plan for how to stay or become well	1	2	3	4
57. There are things that I can do that help me deal with unwanted symptoms	1	2	3	4
58. I know that there are mental health services that help me	1	2	3	4
59. Although my symptoms may get worse, I know I can handle it	1	2	3	4
60. My symptoms interfere less and less with my life	1	2	3	4
61. My symptoms seem to be a problem for shorter periods of time each time they occur	1	2	3	4
Connecting and Belonging				
	Untrue	**A bit true**	**Mostly true**	**Completely true**
62. I have people that I can count on	1	2	3	4

63. Even when I don't believe in myself, other people do	1	2	3	4
64. It is important to have a variety of friends	1	2	3	4
65. I have friends who have also experienced mental illness	1	2	3	4
66. I have friends without mental illness	1	2	3	4
67. I have friends that can depend on me	1	2	3	4
68. I feel OK about my family situation	1	2	3	4

Demographic Information

69. Age (in years) _____

70. Gender: ☐ Female ☐ Male ☐ Other _____

71. Which country do you live in? _____

72. What best describes your current relationship status?

☐ Single
☐ In relationship
☐ De-facto
☐ Married
☐ Separated
☐ Divorced
☐ Widowed

73. Are you currently working?

☐ Full time employment
☐ Part time employment
☐ Casual/temporary employment
☐ Volunteer work
☐ Temporary benefit (Unemployed)
☐ Pension (Aged/Disability)
☐ Student Allowance
☐ Financially dependent on others

☐ Retirement Fund
☐ None

74. If you are currently working, how many hours do you work per week? _____ hours

75. Are you currently studying?

☐ Yes
☐ No

76. What is your highest level of education?

☐ Primary school (Yr 6)/Elementary School
☐ School certificate (Yr 10)/Middle School
☐ Higher school certificate (Yr 12)/High School
☐ University degree (Bachelors, Masters, PhD)
☐ TAFE Qualification/Vocational Education/Diploma
☐ Unknown
☐ None

Open Response Questions

77. In your own words describe where you are in your journey towards recovery from Borderline Personality Disorder (max 1000 words).

78. What are some of the positives or challenges you have experienced on this recovery journey?

Consent for Follow Up Telephone Interview

79. Can we contact you for a 45-minute telephone interview?

☐ Yes
☐ No

80. If yes, what is your email address? _____

If any of these questions have caused you distress, please call LifeLine on 13 11 14 (within Australia). If outside Australia, please contact your nearest doctor or hospital health service.

Thank you for taking the time to complete the survey.

APPENDIX H: Interview Schedule used in Phase Four

1. Can you describe your life at the present moment?
2. Do you think you are on a journey towards recovery? Why or why not?
3. The next few questions are about what your life has been like for you since you started noticing difficulties with BPD
   Prompts
   a. Thinking back to when all this started, what did you experience when you first started noticing that you were having difficulties with BPD?
   b. What was your life like then?
   c. Did you notice your difficulties or did someone else?
   d. Then what happened?
   e. How long did these periods in your life last for?
   f. How does your life differ now compared to when you first noticed your difficulties?
4. What would recovery look like to you?
   a. How would you know when you have reached that stage?
   b. At which stage/point do you consider yourself at the present moment? (and why)
5. Reflecting on the treatment and support you have had so far, what has been the most helpful and least helpful aspects so far?
   Prompts:
   a. What were the most important factors that helped you?
      i. In terms of: services, people, peers
   b. What you do think contributed to the helpfulness of services/people/peers etc?
   c. Were there aspects of your life (other than treatment) that you feel like is contributing to getting well?
   d. In what ways do you think you could have been more supported in getting well?
      i. In terms of: Services, people, peers
   e. If you had to summarise what has helped you the most so far, what are the top five factors?
6. Is there anything else that you think is important that we haven't discussed that you would like to add?

APPENDIX I: Published Version of Manuscript Presented as Chapter Three

PLOS | ONE

RESEARCH ARTICLE

Recovery from Borderline Personality Disorder: A Systematic Review of the Perspectives of Consumers, Clinicians, Family and Carers

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OPEN ACCESS

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Data Availability Statement: All relevant data are within the paper and its Supporting Information files.

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Competing Interests: The authors have declared that no competing interests exist.

Abstract

Purpose

Longitudinal studies support that symptomatic remission from Borderline Personality Disorder (BPD) is common, but recovery from the disorder probably involves a broader set of changes in psychosocial function over and above symptom relief. A systematic review of literature on both symptomatic and personal recovery from BPD was conducted including the views of consumers, clinicians, family and carers.

Materials and Methods

A PRISMA guided systematic search identified research examining the process of recovery from BPD. Longitudinal studies with a follow-up period of five or more years were included to avoid treatment effects.

Results

There were 19 studies, representing 11 unique cohorts (1,122 consumers) meeting the review criteria. There was a limited focus on personal recovery and the views of family and carers were absent from the literature. Rates of remission and recovery differ depending upon individual and methodological differences between studies. Data on symptomatic remission, recurrence and diagnosis retainment suggests that BPD is a stable condition, where symptomatic remission is possible and the likelihood of recurrence following a period of remission is low.

Conclusion

Symptomatic remission from BPD is common. However, recovery including capacities such as engaging in meaningful work was seldom described. Future research needs broader measures of recovery as a sub-syndromal experience, monitoring consumer engagement in meaningful vocation and relationships, with or without the limitations of BPD.

Introduction

Since the deinstitutionalisation of mental health services and the rise of the consumer movement, differences in the conceptualisation of recovery have been proposed in the literature[1, 2]. Recent recovery frameworks have adopted a dimensional approach where, the clearest divide between dimensions has been associated with clinical and personal notions of recovery [3, 4]. Traditional notions of recovery have been clinically based, focused upon the remission of symptoms (or no longer meeting diagnostic criteria) and the return to previous levels of functioning[3–5]. Although Borderline Personality Disorder (BPD) has historically been viewed as an untreatable disorder, more recent longitudinal studies have suggested an upward trend towards remission[6–8] and improvements in levels of functioning[7, 9]. The definitions for remission and reccurence in the literature were similar with high concordance, as they were determined by diagnostic criteria and interview measures. The predominant definition used for remision was no longer meeting the specified criteria for BPD and for recurrence was meeting diagnostic criteria following a period of achieving remission.

An increasing number of psychotherapeutic interventions have been developed specifically for the treatment of BPD. Concerns have been raised over the insufficient evidence available to demonstrate the broader efficacy of these interventions beyond symptom change[10–12]. Randomised control trials comparing identifiably different manualised treatments for BPD have found similarities in the rates of improvement despite purported differences in approach[13]. Given that psychotherapy is the recommended first line intervention for the treatment of BPD, strengthening interventions may improve consumer outcomes[14, 15].

Measuring functional outcomes and symptom remission is important, yet these measurements do not always take into consideration the broader views or lived experiences of consumers or differences in trajectory between individuals. Traditionally in the mental health literature, consumers have challenged this clinical conceptualisation in favour of a holistic view of mental health. 'Personal recovery' (or consumer driven definitions of 'recovery') has been widely described within the literature (see [3, 4, 16, 17]). This review adopts the definition most widely accepted within the recovery literature. Personal recovery is defined as 'a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness' ([16, p527], Given that most clinical trials are only focused on symptom improvement, and reviews of this literature are available, we chose to review studies that have taken a longer perspective (five years or greater) on the journey of people with BPD. In this way we have ensured that we focus our review on longer term outcomes where notions of recovery are likely to become more important.

The lived experience of consumers diagnosed with BPD has attracted some attention in the literature, where research has discussed the impact of the BPD diagnosis[18–20], the stigmatised nature of the disorder[19–21], experiences with treatment[21–24], and consumers' experiences of the disorder[18, 25, 26]. There is no review examining the longer term outcomes of people with BPD. The present study aims to systematically review the literature on longer-term clinical and personal recovery from BPD through the perspectives of consumers, clinicians, family and carers. A comparison between recovery in BPD compared to other mental health disorders will also be explored. Through this, gaps in the literature and future research directions will be identified.

Materials and Methods

The review followed the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) statement[27] in reporting findings of the review (See S1 Table). A predetermined

protocol outlining methods of data searching, inclusion criteria and data extraction method used was registered on the International Prospective Register of Systematic Reviews (PROSPERO, registration number: CRD42015019838).

Articles included for review were identified using a three step process: 1) searching electronic databases, 2) reference list searching and 3) identifying articles known to researchers which complied with the inclusion criteria. Electronic databases searched included; PsychINFO, Psychological and Behavioural Collection, PubMed, Scopus and Web of Science. The same search strategy was used in all databases and included; [(Consumer OR Client OR Patient OR Service User) AND/OR (Clinician OR Therapist) AND/OR (Family OR Carer OR Significant Other)] AND [(Borderline Personality Disorder OR BPD) AND (Qualitative OR Longitudinal) AND (Remission OR Recovery OR Hope OR Psychotherapy OR Therapy OR Client Cent* OR Resilience OR Social Support OR Social Inclusion OR Wellbeing OR Rehabilitation OR Meaning)]. Searches were limited to articles published in English and to research conducted with humans.

Reference lists of sources included in the review were scanned to further identify additional sources. This process was completed twice, firstly on sources identified from the initial electronic database search and secondly on articles identified from the first reference list search. Known sources, particularly recently published articles not identified by the electronic search or reference list search, which complied with the inclusion criteria, were included in the review. One researcher conducted the search and identified articles for inclusion in the review. Articles were initially assessed via their title and abstracts and then in full. Articles eligible for inclusion in the review were checked with an expert in personality disorders. Disagreements were resolved by consensus. One reviewer then extracted data from the included studies, which was checked by a second reviewer. Location of the study, sample, aims, inclusion criteria, data collection methods and tools, major findings and limitations were extracted and coded. To reduce the risk of bias, all articles included in the review were assessed for quality as described below. Qualitative and longitudinal sources were assessed separately using quality assessment tools specific to the methodology.

A predetermined inclusion and exclusion criteria was used to identify articles relevant to the research question. All included studies were required to have BPD as the main disorder under examination and be published in English. Where more than one disorder was examined in an individual study, it was only included in the review if BPD was the main focus of investigation and the other disorders acted as either a comparison group or control group. For example studies which examined the relationship between BPD and other personality disorders was included in the review, so long as they met the other inclusion criteria. As the review aimed to examine the long-term outcomes of BPD, the review was interested in the symptomatic remission and consumer understandings of recovery. All perspectives from consumers, families, carers or clinicians were included in the review to gain a holistic view of recovery. Studies were included in the review if the participants described were within the community or inpatient settings at the time of data collection. This however, excludes all patients from the forensic system with the BPD diagnosis, including consumers in forensic psychiatric inpatient units and their carers and clinicians. This is due to the association between BPD and antisocial personality disorder which is prevalent within forensic settings and not the focus of the present review.

The mention of treatments received by patients within individual studies did not lead to its exclusion, however studies that were conducted with intention to evaluate the effectiveness of specific interventions or comparative treatment studies were excluded from the review. This was due to the aim to examine the long-term outcomes of BPD rather than study treatment effects or treatment trial implementation. Due to this treatment trials with a follow-up period

of less than five years were also excluded. No restrictions were placed on the publication period.

The quality of longitudinal studies was assessed using a criteria adapted from Kuijpers and colleagues[28] and Luppino and colleagues'[29] review which evaluated domains including study population, baseline and follow-up measures and the measurement tools used, and has been widely used in previous research (for example [30, 31]). Items on the quality assessment criteria were scored using a plus, minus or question mark. A score of one was given to items rated as a plus and a score of zero was given to items rated as a minus or question mark (See S2 Table). Studies were required to score at least six out of ten quality criteria in order to be included for review [28, 29]. Included studies scored highly on all domains assessed, however common domains that studies did not fulfil included having less than 75% of the initial cohort included in the study, having a dropout rate greater than 20% at follow-up, and diagnosing study participants with BPD without a clinical interview.

Quality of qualitative studies was assessed using a combination of assessment tools which examined credibility and rigour. The quality assessment criteria developed by Kuper, Lingard and Levinson[32] assessed domains including the sample, data collection, analysis, transferability of results, ethical consideration and coherence of the study. Studies were ranked as 'very good', 'good', 'acceptable' or 'unclear', where an 'acceptable' or above score in four of the six domains was required in order to be included in the review. Qualitative studies were also classed on the hierarchy of qualitative evidence[33], which ranged from single case studies (least likely to produce good evidence for practice), descriptive studies, conceptual studies and generalisable studies (strongest) (See S3 Table). These methods of appraising qualitative research have been used in a number of studies[34–36]. All domains assessed from the included qualitative articles was ranked 'acceptable' or higher, except in one domain in Lariviere and colleagues'[18] where it was unclear if ethical issues were considered.

A thematic synthesis approach adapted from Thomas and Harden[37] was used to identify key themes from included studies. A three step process involving: 1) line by line inductive coding of the results section of included studies, 2) translation of codes into descriptive themes, and 3) the development of analytical themes was used. Multiple codes were used to encapsulate the meaning and content of findings in line by line coding. Descriptive themes were developed through translating codes. The synthesis of descriptive themes to analytical themes was guided by the research question of the review which incorporated the theoretical conceptualisations of recovery. The trustworthiness of the data was ensured through consistent discussion amongst the research team about emerging codes and themes, where discrepancies were resolved via consensus.

Results

Search Results

A total 697 sources was identified through electronic database searching (n = 426) and identifying additional sources (n = 271). Following the application of limits (to the English language and research conducted with humans) and the removal of duplicates, 514 sources were screened through their title and abstract. A total of 479 sources were excluded from the review, as they did not meet the inclusion criteria. Of the remaining 35 sources, 16 sources were excluded due to sources not being empirical in nature (n = 1), not related to recovery or remission (n = 12), follow-up period in longitudinal studies was less than five years (n = 2) or the methodology was not longitudinal or qualitative in nature (n = 1). The remaining 19 sources were included for review, consisting of 16 longitudinal studies and three qualitative studies (See Fig 1).

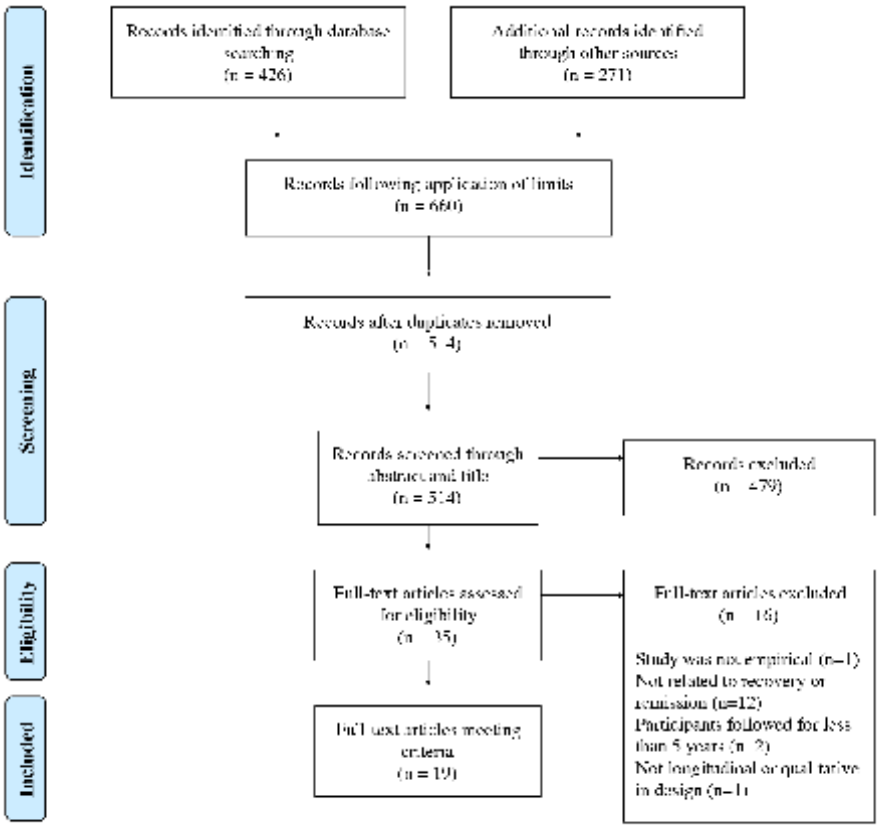

Fig 1. PRISMA flowchart for the selection of studies included in the systematic review.

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Study Characteristics

Overview of quantitative studies. Of the 19 included studies, 16 studies were longitudinal in nature (See Table 1). The range of publication years lead to differences in the method used to assess patients for diagnosis of BPD where chart analysis (n = 9) [6, 7, 9, 38–43] and clinical interviewing (n = 7) [8, 44–49] was used. Studies predominately used the Diagnostic and Statistical Manual of Mental Disorders—Third Edition criteria (DSM-III; n = 5) to determine the inclusion of participants and in assessing remission, recurrence or diagnosis retainment status, whilst others used the Diagnostic Interview for Borderlines (DIB; n = 4), DSM Fourth Edition (DSM-IV; n = 1), DIB and DSM-III-R (n = 4) or the DSM-III and Gunderson and Kolb[50] criteria (n = 2). Several measures of functioning were used depending on when the study was conducted, these included the Health Sickness Rating Scale (HSRS; n = 4), the Global Assessment Scale (GAS; n = 4) and the Global Assessment of Functioning (GAF; n = 5) although these are all highly similar. Three studies did not measure a participant's level of functioning. All quantitative studies met the quality appraisal criteria and all were included for review.

Table 1. Characteristics of included studies.

Source	Study type	Location	Sample	Aim	Inclusion criteria	Data collection and measures used	Findings	Limitations
[6]	Longitudinal (follow-upon average 27 years)	Canada	Patients with BPD (n = 84)	To follow-up patients to examine whether symptomatic relapses occur during later middle age.	• Part of the previous follow-up phase[45]	• DIB-R • SCID • GAF • SCL-90 • SAS-SR	Significant decrease in the prevalence of BPD and the number of criteria still met in the sample. No significant differences in functioning over the baseline and follow-up period, however attributed this to use of different scales and it is proposed that there is a limit on the level of improvement in patients with BPD..	Chart review was used to identify patients meeting criteria for BPD.
[7]	Longitudinal (follow-upon average 15 years, range = 2–32)	United States	Patients with BPD (n = 81), Schizophrenia (n = 163) and Unipolar affective disorder (n = 44)	To examine the long term course and outcomes of individuals diagnosed with BPD compared to patients with schizophrenia or UNI..	• Patients discharged from Chestnut Lodge between 1950 and 1975. A select number of non-discharged patients were also included • Patients without organic brain syndrome • Aged between 16 and 55 years • Inpatient for a minimum of 90 days	• Used chart analysis to re-diagnose patients • BPD: (DSM-III criteria, Gunderson and Kolb [8,9]. • Schizophrenia: (New Haven Schizophrenia Index, Feighner and colleagues[8,9] criteria, Research Diagnostic Criteria) • MDD and Schizotypal PD: (DSM-III criteria)	Diagnosis of BPD remained stable over the follow-up period.. Use of services was a similar rate in consumers with BPD and UNI but higher in patients with schizophrenia. Compared to patients with UNI or schizophrenia, patients with BPD have better levels of vocational engagement, global outcomes (hospitalisation and symptoms experienced). Full recovery was perceived as unachievable due to chronicity of disorder and individual character..	The study used chart analysis to identify potential patients, however more than 20% of participants dropped out of the study at follow-up. The study does not discuss treatments participants have engaged in..
[8]	Longitudinal (follow-upat 16 years)	United States	Patients with BPD (n = 231)	To determine the time needed to reach and the stability of symptomatic remission and recovery in patients with BPD	• Aged between 18–35 years • IQ above 71 • No history of schizophrenia, schizoaffective disorder, bipolar I or organic conditions • Fluent in English	• Semi-structured Interviews: • Background Information Schedule • Structured Clinical Interview for DSM-III-R Axis I disorders • Revised Diagnostic Interview for Borderlines • Diagnostic Interview for DSM-III-R Personality Disorders	Symptomatic remission for a two year period was achieved by 99% of participants. Compared to other Axis II disorders, BPD had a slower remission rate. Recovery occurred slowly and there was a higher risk of relapse compared to other disorders. Vocational participation impacted upon obtaining recovery.	Patients were recruited from an inpatient setting which may influence functioning scores and may not be representative of the general population.. Difficulties with comparing GAF scores as scores at baseline and follow-up were not presented.. The types of treatment consumers engaged in during the follow-up period are unclear..
[9]	Longitudinal (follow-upon average 13.6 years	United States	Study drew a from a larger sample (N = 237) however, reports on patients with 'pure' BPD (n = 43), BPD and SPD (n = 6), BPD and SDPD (n = 5), BPD and MDD (n = 9), schizophrenia (n = 19), MDD (n = 24), SPD (n = 13)	To examine the functioning of patients with BPD or SPD compared to schizophrenia, MDD and other disorders.	• Admitted to Austen Riggs Center for at least 2 months between 1950 and 1976	• GAS	Patients with BPD had better levels of functioning than patients with schizophrenia, however no difference with patients with MDD.. BPD and MDD group was found to be functioning worse than aggregated BPD group which is inconsistent with the previous literature..	Differences in sample size between groups in the study, reliability of results is questionable.
[10]	Qualitative	Canada	12 female service users from two BPD specialist services in Quebec, Canada.	To capture the recovery experiences of women from BPD through analysis of experiences through the PEO model.	• Participants had to be female, diagnosed with BPD, be aged between 18 and 65 years and had completed 2 years of treatment for BPD in a specialised service..	• Creation of a picture collage, two semi-structured interviews and review of medical records. • Thematic analysis of semi-structured interviews	Consumers associated recovery with personal development, greater emotional control, assertiveness, interpersonal relationships, having meaningful roles/ vocation and letting go of the past and looking towards the future. It is suggested that the concept of wellbeing may better encapsulate the experiences of consumers than 'recovery'.	Small sample size and only included the perspectives of female consumers. Analysis completed in line with PEO model, may have missed perspectives that did not fit within the categories

(*Continued*)

Table 1. (*Continued*)

Source	Study type	Location	Sample	Aim	Inclusion criteria	Data collection and measures used	Findings	Limitations
[29]	Qualitative	United Kingdom	Consumers with BPD (n = 46)	To gain understanding into the goals and aspirations of service users to better understand views of recovery	• Individuals that were over 18 years of age, diagnosis of BPD and history of self-harm (self-injurious behaviour, overdose or suicide attempts)	• Semi-structured interviews • Grounded theory and thematic analysis	Consumer recovery goals were associated with improving symptoms of BPD and engaging in meaningful activities. However consumers did not believe specialised treatments for BPD prioritised their goals. Level of recovery fluctuated within participants where most acknowledged that they had improved but not fully recovered. This led to questions of whether 'recovery' encapsulated their experiences.	Limited to perspectives of consumers. Study conducted in one location.
[34]	Longitudinal (follow-up range: 4–7 years)	United States	Patients with Borderline Personality Disorder (n = 33)	To examine the validity of the BPD diagnosis and compare BPD to DSM-III schizophrenia, MDD and other PDs.	• Inpatient at McLean Hospital between 1974 and 1977 • Aged over 18 years • Based on hospital records received a score of 6 or more on the DIB • Met DSM-III diagnostic criteria for BPD	• DSM-III • DIB	Differences between patients with BPD, BPD and MDD and schizophrenia were identified. BPD and schizophrenia diagnosis was stable, however the BPD diagnosis was less stable in patients with BPD and MDD. Comorbidity with MDD predicted better functioning and symptom remission.	The study had a small sample size and over half of the sample also met criteria for DSM-III Major Affective Disorder.
[35]	Longitudinal (follow-up average 15 years after discharge, ranged between 2–32 years)	United States	Patients with BPD (n = 81)	To identify outcome predictor variables for BPD and examine the applicability of schizophrenia predictor variables for BPD.	• Without organic brain syndrome • Between 16 and 55 years at admission • Treated at Chestnut Lodge for at least 30 days	• Diagnosis assigned through transposition of medical records to the chart abstract. • Based on 56 demographic/ predictor variables and 49 signs and symptom variables. • Standard Follow-up Interview Battery and Extended Interview Follow-up Battery (see [53])	Diagnosis of BPD remained stable at follow-up with approximately 50% of patients experiencing moderate levels of symptoms. Patients with BPD accessed treatment at the same rate as patients with UNI but at a lower rate than patients with schizophrenia. Patients with BPD were more likely to be engaged in vocation and had higher global outcomes.	The study used chart analysis to identify potential patients, however more than 20% of participants dropped out of the study at follow-up. The study does not discuss which treatments participants have engaged in.
[40]	Longitudinal (follow-up on average 13.6 years	United States	Study drew a from a larger sample, however reports on patients with BPD only (n = 33)	To identify predictors of outcome in BPD.	• Admitted to Austen Riggs Center for at least 2 months between 1950 and 1975 Minimal comorbidities with affective disorder, substance abuse or other PDs.	• GAS	Strongest predictors of outcome in patients with BPD were associated with demographic variables. Symptoms of personality disorder were identified to predict poorer social and vocational prognosis at follow-up. Poorer vocational outcomes were also predicted by experiences of chronic emptiness or boredom. Did not find the link between higher IQ and better outcomes.	Limited sample of patients with BPD.
[41]	Longitudinal (follow-up at 16 years)	United States	Patients diagnosed with BPD and schizophrenia	To describe the global outcomes of patients with BPD	• Admitted to the General Clinical Service at New York State Psychiatric Institute for at least 3 months	• Chart analysis • DSM-III criteria • Guidelines for BPD by Kernberg[54] • GAS	Patients with schizophrenia were more likely hospitalised during the follow-up period compared to patients with BPD, similarly observed in rates of institutionalised care during follow-up. More patients with BPD were able to work at least 50% of the follow-up, however patients with schizophrenia were identified as most 'handicapped'.	Use of chart review to diagnose patients. Does not discuss remission, recurrence or readmitment rates

(*Continued*)

Table 1. (*Continued*)

Source	Study type	Location	Sample	Aim	Inclusion criteria	Data collection and measures used	Findings	Limitations
[42]	Longitudinal (follow-up at 16 years)	United States	Patients diagnosed with BPD (n = 205)	To describe the global outcomes of patients with BPD	• Patients admitted into New York State Psychiatric Institute between 1963–1975	• GAS	Consumers with BPD had higher levels of functioning and most reached a 'clinically well' stage compared to patients with schizophrenia. Patients with comorbid MDD had higher levels of functioning than patients with BPD only. Similar suicide rates in BPD and schizophrenia groups.	Baseline data on functioning scores is not provided and the types of treatment received by patients is not clear
[43]	Longitudinal (follow-up for an average of 15 years)	Canada	Patients with BPD (n = 100)	To examine long term outcomes of patients with BPD being treated in a general hospital	• Diagnosis of BPD or retrospective diagnosis of BPD	• DIB • HSRS • Schedule for Follow-up of Borderline Patients	Quarter of patients still met criteria DIB for BPD. Patients at follow-up was functioning better however still had some difficulties. Work history, relationships and family adjustment was at a comparable level to outpatients. Social functioning improved due to less chaotic relationships, however dysphoria, younger age at diagnosis and family history predicted worse outcomes.	Chart review was used to identify patients meeting criteria for BPD. No comparison score for HSRS at baseline. Unable to determine significance of change at follow-up. Limited patient demographic information provided. Effects of treatment unclear from data.
[44]	Longitudinal (6 year follow-up)	United States	Patients with BPD (n = 290)	To examine the six year course of syndromal and sub-syndromal BPD.	• Aged between 18 and 35 years • IQ of 71 or higher • No history of an organic condition, schizophrenia, schizoaffective disorder or Bipolar I Fluent in English	• SCID DIS-R • Background Information Schedule	Remission from BPD was common and increased with every follow-up phase. At two year follow-up, 34.5% of consumers had achieved remission. Over the six year period, 73.5% of consumers had experienced remission. Only 5.9% of consumers experienced recurrence.	Participants were recruited from an inpatient setting and may not be representative of the general population. Treatment engagement is unclear.
[45]	Longitudinal (follow-up at 7 years)	Canada	Patients with borderline psychopathology (n = 88) or traits (n = 44)	Aimed to examine the relationship between borderline psychopathology and other clinical disorders at follow-up	• Aged between 18 and 65 at admission • Inpatient in acute psychiatric setting Clinical diagnosis of BPD or at least 3 of 7 borderline characteristics as described by Gunderson and Kolb [46]	• SADS • RDC • DIB	At follow-up 47.4% of patients retained the BPD diagnosis. Persistent group more likely to be diagnosed with other clinical disorders compared to the remitted group, however no differences in the number of depressive episodes between these groups were identified. 'New' BPD group had higher episodes of depression. Borderline psychopathology at baseline was predictive of other clinical disorders at follow-up.	More than 20% of participants dropped out of the study which lead to a no over proportion of females in the sample. Types of treatment received by participants is unclear.
[46]	Longitudinal (10 year follow-up)	United States	Three study groups; BPD (n = 175), cluster C PD (n = 312) and MDD (n = 95)	Compare course of BPD (symptoms and functioning) with other PDs and MDD	• Participants had to be 18–45 years old who have received psychiatric care and met criteria of screening tools including PSQ, DIPD-IV, PAF, SNAP	• DIPD • DSM-IV • GAF • Same measures used at baseline, 6 months and 12 months and 2,4,6,8 and 10 years.	Significant proportion of patients (91%) achieved remission and relapse was less common in BPD compared to other disorders. Patients with BPD had poorer levels of functioning compared to patients with OPD and MDD at follow-up. Older age predicted poorer functioning and higher levels of education predicted higher levels of functioning. Engagement in vocation and marital status improves over time.	Study does not provide information on the treatments received by consumers and does not take into consideration the views of consumers

(*Continued*)

Table 1. (*Continued*)

Source	Study type	Location	Sample	Aim	Inclusion criteria	Data collection and measures used	Findings	Limitations
[47]	Longitudinal (follow-up at 7 years)	Canada	Patients diagnosed with Borderline Personality Disorder (n = 88) and patients with borderline traits (n = 44)	Aimed to examine the persistence of BPD and occurrence of other personality disorders at follow-up. To identify the predictive value of personality disorder psychopathology in determining severity of BPD and other PDs at follow-up.	• Aged between 18 and 65 at admission • Inpatient in acute psychiatric setting • Clinical diagnosis of BPD or at least 3 of 7 borderline characteristics as described by Gunderson and Kolb [66]	• SADS • RDC • DIB • GAS • SIDP-R	At follow-up 47.4% of patients retained BPD diagnosis and patients with persistent BPD had a higher incidence of other PDs. Persistent and 'new' groups had a similar number of comorbid PDs. DIB level of psychopathology at baseline was predictive of borderline psychopathology and self-defeating behaviours at follow-up.	More than 20% of participants dropped out of the study which led to an over proportion of females in the sample. Type of treatment received by participants is unclear.
[48]	Longitudinal (based on 10 year follow-up data)	United States	Patients with BPD (n = 249)	To determine which variables best predict remission from BPD	• Aged between 18–35 years • IQ above 71 • No history of schizophrenia, schizoaffective disorder, bipolar I or organic conditions • Fluent in English	• Semi-structured Interviews • Background Information Schedule • SCID • DIB-R • DIPD	The amount of time for remission was found to be predicted by younger age, no prior hospitalisations, no history of child sexual abuse, low levels of verbal, physical and emotional abuse and limited witnessing of violence. Higher levels of childhood competence and the absence of family history of mood or substance disorder decreased the time to remission. Not having comorbidities with PTSD or anxious cluster personality disorders, having normal personality traits and a good vocational record decreased time to remission.	Patients were recruited from an inpatient setting which may influence functioning scores and may not be representative of the general population. Difficulties with comparing GAF scores as scores at baseline and follow-up were not presented. The types of treatment consumers engaged in during the follow-up period were unclear.
[49]	Longitudinal (10 year follow-up)	United States	Patients with BPD (n = 249)	Continuation of the McLean Study of Adult Development which aimed to examine the rates of symptom remission, recovery and sustained recovery in BPD.	• Aged between 18–35 years • IQ above 71 • No history of schizophrenia, schizoaffective disorder, bipolar I or organic conditions • Fluent in English	• Semi-structured Interviews: • Background Information Schedule • SCID • DIB-R • DIPD	Symptomatic remission was achieved by the majority of participants (98%) where 86% of participants were able to maintain for a four year period. Recovery was identified to be more difficult to achieve, however was stable once attained. Difficulties with functioning still observed at 10 years.	Patients were recruited from an inpatient setting which may influence functioning scores and may not be representative of the general population. The types of treatment consumers engaged in during the follow-up period are not clear.
[51]	Qualitative	Norway	Thirteen female service users	To identify how the recovery process leads to changes in suicidal behaviour	• Participants had to be female with a diagnosis of BPD	Thematic analysis of semi-structured Interviews	Recovery process facilitated changes to suicidal behaviours, by increasing consumers' desire to take responsibility for self, being understood and refusing to be defeated by the disorder. Self-development assisted with developing trust and a sense of safety with self and others.	Only the perspectives of female consumers were considered and the study had a small sample size

BPD, Borderline Personality Disorder; DIB, Diagnostic Interview for Borderlines; DIB-R, Revised Diagnostic Interview for Borderlines; DIPD-IV, Diagnostic interview for DSM-IV Personality Disorders; DSM-III, Diagnostic and Statistical Manual for Mental Disorders–Third Edition; DSM-IV, Diagnostic and Statistical Manual for Mental Disorders–Fourth Edition; GAF, Global Assessment of Functioning; GAS, Global Assessment Scale; HSRS, Health-Sickness Rating Scale; IQ, Intelligence Quotient; MDD, Major Depressive Disorder; OPD, Other Personality Disorder; PAF, Personality Assessment Form; PD, Personality Disorder; PEO, Person-Environment-Occupation; PSQ, Personality Screening Questionnaire; RDC, Research Diagnostic Criteria; SADS, Schedule for Affective Disorders and Schizophrenia; SAS-SR, Social Adjustment Scale; SCID, Structured Clinical Interview for DSM-III-R Axis I Disorders; SCL-90, Symptom Check List-90; SDPD, Schizoid Personality Disorder; SIDP-R, Structured Interview for DSM-III-R Personality; SNAP, Schedule for Non-adaptive and Adaptive Personality; SPD, Schizotypal Personality Disorder.

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Overview of qualitative studies. From the 19 included studies, three studies were qualitative in methodology[18, 22, 51], which aimed to gain an understanding of the recovery process from BPD through the perspectives of consumers (See Table 1). Two studies were conducted in Europe and the other in North America. All studies were conducted using semi-structured interviews, however differed in analysis technique where one study analysed responses through a grounded theory approach[24], whilst the remaining studies used thematic analysis[18, 51]. Articles represented different professional backgrounds including psychology, occupational therapy and nursing. All qualitative studies were appraised using the Kuper, Lingard and Levison [32] guidelines and all were rated above the 'acceptable' standard. Studies were also ranked using the Daly and colleagues[33] hierarchy of evidence were two studies were categorised as conceptual studies[22, 51] indicating that theoretical frameworks guided the recruitment and analysis of results which reflected participant's views. The remaining study was categorised as a descriptive study[18] where the article described the participant's view in a practical rather than theoretical manner. All studies met the minimum quality criteria and were included for review.

Sample Characteristics

To avoid duplication of participants, longitudinal studies that had more than one published follow-up article were not all included in the sample characteristics. In these cases, only the baseline study of the specific cohort was counted. Overall, the 19 included studies represented 11 unique cohorts of participants (eight cohorts from included longitudinal studies and three cohorts from included qualitative studies), equating to a total of 1122 individual consumers with BPD. Consumers represented in the included studies were predominately female (72.5%) from a Western background (84.6%) with an average age of 30.3 years. Most were never married (63%) and were not engaged in a vocation (64.9%).

Main findings from quantitative studies

The findings from the quantitative studies were categorised into three major themes: 1) remission, recurrence and diagnosis retainment rates, 2) level of functioning, 3) predictors of outcomes, and 4) differences between BPD and other disorders.

Remission, recurrence and diagnosis retainment rates. Definitions used to identify remission, recurrence and diagnosis retainment rates were determined by the definitions used by the included studies. As such remission rates represented patients who had previously met the specific diagnostic criteria for BPD but did not meet criteria at follow-up. Similarly, recurrence refers to patients who had previously achieved a state of remission, however experience symptoms meeting the diagnostic cut-off at follow-up. Diagnosis retainment was defined and represented by patients who met diagnostic criteria during one follow-up wave and continued to meet criteria at the next follow-up wave, thus retaining a diagnosis of BPD.

The follow-up period of studies discussing remission, recurrence, and diagnosis retainment ranged between 4 and 27 years. Data on remission rates were available in five cohorts (representing nine studies)[6, 8, 38, 43–47, 49], where rates ranged between 33–99% of patients. Table 2 shows the five studies and includes the follow-up timeframe the proportion in remission. Reccurence rates were avaliable for two cohorts (representing four studies)[8, 44, 46, 49], ranging between 10–36% of patients,. Table 3 shows the recurrence rates and follow-up duration. Retainment rates were available for four cohorts (representing six studies)[6, 38, 43, 45–47] ranging between 7.8–66.7% of patients as shown in Table 4.

Level of functioning. Most longitudinal studies examined the level of functioning of patients within their cohorts. All functioning scales used in the included studies (HSRS, GAS

Table 2. Rate of Remission from BPD Across Five Cohorts Representing 585 Participants.

Cohort	Sources	Remission Rates		
		Sample Size	Remission Proportion	Follow-up in Years
1	[38]	27	33.3%	4–7
2	[45, 47]	88	52.6%	7
3	[6, 43]	64	92.2%	27
4	[46]	175	85%	10
5	[8, 44, 49]	231	99%	16

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and GAF) are revisions of the HSRS. Due to similarities across the scales, all ratings of functioning were pooled together to be representative of all included studies in the review. Overall, the findings indicate that despite substantial increases in functioning in patients with BPD, this level of functioning is still indicative of ongoing difficulties.

Baseline functioning ratings were provided by three studies[9, 44, 46], representing 519 patients. Aggregated baseline functioning ratings resulted in an average score of 42 (range = 35–53), indicating that patients experienced serious symptoms and serious limitations in functioning[55]. Follow-up patient functioning was rated in six studies[6, 7, 9, 42, 43, 46], representing 679 patients. Despite differences in the length of follow-up, the average length of follow-up was 16 years (range = 10–27 years). Aggregated functioning scores at follow-up resulted in an average score of 63 (range = 57–67). Patients were considered functioning well, however experienced mild symptoms and continuing difficulties with vocational functioning [55]. The change between baseline (42) and follow-up (63) functioning scores was substantial [56].

Predictors of outcomes. Seven studies examined variables that were predictive of outcomes[39, 40, 43, 45–48]. Being diagnosed at a younger age, without experiences of childhood sexual abuse or a family history of substance abuse predicted a faster rate of recovery[48]. This was exemplified by findings that suggest familial experiences, such as substance abuse, history of mental illness and divorce, were predictive of negative outcomes[39, 40]. Discrepancies however arose over the protective ability of being diagnosed at a younger age and having higher levels of educational attainment and intelligence, as these were not replicated across studies[39, 40, 43, 46].

Illness manifestation variables were identified to be the strongest predictors of global outcomes in patients with BPD, however discrepancies in the predictive ability of the illness course, admission index, demographic and background variables were identified. Meeting Gunderson and Kolb's[50] criteria for BPD, experiencing personality disorder traits or affective symptomatology with dysphoric features was associated with poorer outcomes, however lower levels of psychosocial stress was a protective factor[39, 43]. Clinical indicators of faster rates of remission were associated with personality traits including low neuroticism, high agreeableness and the absence of anxious cluster personality disorders[48]. Hospitalisations were predictive

Table 3. Rate of Recurrence from BPD Across Two Cohorts Representing 406 Participants.

Cohort	Sources	Recurrence Rates		
		Sample size	Recurrence Proportion	Follow-Up in Years
4	[46]	175	• 21% (following 12 months of remission) • 11% (following of 10 years remission)	10
5	[8, 44, 49]	231	• 36% (following 2 years of remission) • 10% (following 8 years of remission)	16

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Table 4. Rate of Diagnosis Retainment from BPD Across Four Cohorts Representing 354 Participants.

Cohort	Sources	Diagnosis Retainment Rates		
		Sample size	Retainment Proportion	Follow-Up in Years
1	[38]	27	66.7%	4–7
2	[45, 47]	88	47.4%	7
3	[6, 43]	64	7.8%	27
4	[46]	175	9%	10

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of the illness course where the length of prior admissions predicted the length of future admissions[40]. However, the predictive ability of hospitalisations on outcomes was inconsistent where some studies found that longer hospitalisations lead to poorer outcomes[39], whilst other studies found no difference[40].

Differences between BPD and other disorders. Ten studies included in the review examined the association of BPD with other disorders. Common disorders examined included schizophrenia (n = 4), major depressive disorder (MDD, n = 4) and other personality disorders (n = 4). Differences in remission rates and functioning (as measured by standardised measures including the HSRS, GAS and GAF) were identified between disorders, such that patients with BPD had higher levels of functioning than patients with schizophrenia but not other personality disorders[9, 42]. Contradictory results with MDD were noted where some studies found patients with BPD functioned more poorly[46] whereas others found no difference[7]. Results examining concomitant MDD with BPD were also contradictory such that some studies found poorer outcomes in patients with MDD and BPD compared to BPD alone[7]. Rates of remission differed between the disorders such that BPD remitted at a slower rate compared to MDD and other personality disorders[8, 46, 49] but faster than schizophrenia[53]. This suggests that patients with schizophrenia have poorer outcomes compared to patients with BPD; however it is unclear as to whether patients with MDD and other personality disorders have better outcomes than patients with BPD.

Main findings from qualitative studies

Themes from the qualitative studies depicted consumer goals and factors that facilitated their recovery, however despite the ability to identify recovery or treatment goals, the conceptualisation of recovery was questioned. The consumer perceptions of their recovery fell into three broad themes; 1) active willingness to engage in the recovery journey, 2) improving on clinical characteristics of BPD to facilitate change and 3) the conceptualisation of recovery.

Active willingness to engage in recovery journey. This theme was articulated across all qualitative studies where the desire for recovery was a prerequisite for change in other recovery dimensions[18, 22, 51]. Studies identified that active willingness was initiated through the desire for meaningful roles, vocation and motivation to not be defeated by the disorder. Consumer engagement in a vocation or activities, such as completing daily tasks (e.g. paying bills), education, therapy or developing a career, facilitated change and provided a sense of achievement, competence and routine[18, 22, 51].

Having a sense of defiance to being defined or defeated by the disorder was identified by studies to promote consumer's willingness to engage in the recovery process[51]. Gaining greater insight into BPD, through psychoeducation and therapy, facilitated recovery through the provision of a new language to communicate inner states and needs, in order to respond in an emotionally regulated manner and increase consumer's awareness of the functions of behaviour.

Improving on clinical characteristics of BPD to facilitate change. The ability to improve upon three clinical characteristics of BPD: 1) emotion regulation, 2) developing a sense of identity, and 3) improving interpersonal skills and relationships, were necessary in order to engage in other aspects of recovery.

The need for better 1) emotion regulation was reported by all studies, such that having a greater emotional experience facilitated recovery in other areas of consumer's lives. The ability to tolerate intense positive and negative emotions without the urge to engage in maladaptive behaviours was a priority. Similarly, despite the ability of self-harm to abate suicidal ideation, the reduction of self-harming behaviours promoted personal development in areas including identity formation and interpersonal relationships.

Developing 2) a sense of identity was an initial internal motivator for change that occurred through the acknowledgment of past experiences, developing a sense of self separate from others, and understanding the BPD diagnosis. The process of redefining identity commenced through a shift away from the passive and victim persona and the acceptance of past experiences to focus on the present[18, 22]. Although these were observed to reduce self-critical thoughts and promote self-acceptance, difficulties associated with the misunderstanding and misinterpretation of a consumer's intention by others was observed to hinder this process[51]. For example, suicide attempts were identified as selfish and inconsiderate rather than fulfilling an emotion regulation function[51]. Studies noted that the misinterpretations of others exacerbated the stigma perceived by consumers, perpetuating their negative perception of self, however gaining understanding into BPD provided behavioural insight and greater self-acceptance. Furthermore, developing a sense of identity separate from others was associated with the development self-confidence[18]. The ability to express emotions and ask for needs to be met was facilitated through the development of assertiveness and was perceived as a sign of recovery.

Strengthening 3) interpersonal skills and relationships, was identified by studies to assist in widening a consumer's social network and provided opportunities to translate skills from therapy[18, 22, 51]. Positive benefits included learning to tolerate feelings of abandonment and rejection, and dealing with or ending dysfunctional relationships[18, 22]. Studies identified that having a sense of trust was essential in developing stronger relationships with others. However, this was paradoxical as a level of trust prior to entering into a relationship was required [18]. A trusting relationship with the health system was particularly highlighted such that health professionals acted as an extended support network that could be drawn upon during times of need[18, 51]. However, stigma associated with the diagnostic label hindered trust formation and a consumer's ability to fully engage[51]. Similarly, family and friends were also viewed to be an extended support network.

The development of interpersonal skills was noted by studies to assist in the improvement of the reflective capacity of consumers, allowing for greater insight into the impact of one's behaviour on others[22]. This was identified as a particularly important skill as the ability to empathise with others during periods of distress was diminished[51].

The conceptualisation of recovery. The conceptualisation of recovery from BPD was discussed by two of the three qualitative studies[18, 22]. Studies discussed consumer's concerns as to whether the word accurately encapsulated their experiences. The dichotomous understanding of recovery was identified as an issue, as consumers viewed the synonymous conceptualisation of recovery and cure as unrepresentative of their experiences with BPD. Additionally, clinical implications were highlighted such that 'black and white' thinking may contribute to delays in help seeking. Alternative conceptualisations offered by studies described consumer experiences as a "journey", "progress" or "learning"[18, p6]. This was particularly demonstrated within discussion about personal recovery goals where the multifaceted nature was emphasised. Recovery goals were associated with personal development (such as developing

greater control over emotions and negative thinking patterns), developing interpersonal relationships and participation in activities and vocation (such as day to day activities, education or employment). Differences in the service defined understanding of recovery elicited frustration in consumers, where aspects of clinical recovery (including the reduction of symptoms) was emphasised. For example, the emphasis on specific behavioural change in some treatments may not always align to individual recovery goals[22]. Difficulties with emotion regulation and interpersonal relationships were continual challenges for consumers meaning full remission may not be achieved. Katsakou and colleagues'[22] study described consumer's recovery in stages from no progress to recovered.

Discussion

The review aimed to examine the clinical and personal conceptualisation of recovery from BPD through the perspectives of consumers, clinicians, family and carers. Despite the aim, most of the current literature to date was focused upon the clinical recovery of consumers with BPD. Clinician and observer ratings (e.g. of functioning) and consumer ratings (e.g. of symptoms) predominated. Although research into BPD has increased, limited attention has been placed on the lived experience of consumers and their support networks. The earliest article examining recovery from a consumer's perspective was published as recently in 2011 and no articles on the recovery experiences from the perspective of clinicians, family and carers were identified. Overall, nineteen articles met the pre-determined inclusion criteria and were thematically synthesised, where four major findings emerged from the review.

Remission, recurrence, and diagnosis retainment of BPD

Although rates of remission, recurrence and diagnosis retainment rates from BPD have been identified across a number of longitudinal studies, significant differences in how these concepts have been defined exist between studies. Remission rates ranged between 33–99%, whilst recurrence and retainment rates ranged between 10–36% and 7.8–66.7% respectively. Due to large variability within these rates, it is difficult to identify the exact proportion of patients who will experience remission, recurrence or diagnosis retainment in any given time period because of the use of various methodologies. These differences include; 1) the diagnostic tool used, 2) length of follow-up, 3) patient drop-out rate, 4) methods used to locate patients at follow up, and 5) the setting in which patients were recruited (inpatient or outpatient).

Differing cut-off requirements influences the proportion of patients that are considered remitted, experience recurrence, or those retaining the diagnosis. Patients in two cohorts[38, 45, 47] were assessed using the DIB however differed in cut-off requirements. Pope and colleagues' [38] study endorsed a lower cut-off requirement (6 points) which may partially explain lower rates of remission and higher rates of diagnosis retainment within the cohort, compared to a relatively higher remission (7 point cut off requirement) and lower retainment rates found in Links and colleagues'[45, 47] cohort. The Pope and colleagues' study[38] was also of severe multi-diagnostic cases seen before the first randomised controlled studies of treatment for BPD had been published.

The time period in which patients are followed up should also be considered, which in this review spanned between 4 and 27 years. Cohorts with longer follow-up periods, that is greater than 10 years[6, 8, 43, 44, 46, 49], have higher rates of remission, indicating that the experience of symptoms reduce with increasing age. This may be partially explained by previous research which has suggested that the experience of impulsivity in BPD reduces with increasing age[57], whilst other reasons proposed in the literature have included the effects of social learning over time and the avoidance of intimate relationships[58]. The stability of the disorder has been

highlighted in other studies, such that BPD criteria followed a similar reduction trend[46]. Variability within recurrence rates was also associated with the time period as defined by researchers, where rates ranged between 10–36%[8, 44, 46, 49]. As expected, higher rates of recurrence (21–36%) were observed following shorter periods of remission (one to two years) and lower rates of recurrence (10–11%) following extended periods (8–10 years) of remission. Despite recurrence only being examined in two cohorts, these findings are low and clinically promising, suggesting that once a state of symptomatic remission is achieved, the likelihood of recurrence is low.

High drop-out rates of greater than 20% at follow-up may have led to the overestimation of the remission rate in three cohorts, resulting from being lost to follow-up, refusal to participate, suicide or death by natural causes[6, 43, 45–47]. Despite this, all studies engaged in a similar method of locating patients at follow-up (contacting patients via mail, phone or their therapists) and may favour individuals who are less engaged in vocation or have lower levels of functioning as they continued in treatment.

The variability in retainment rates appeared to be influenced by the range of follow-up years and where patients were recruited. Shorter follow-up periods were associated with a higher diagnosis retainment rate, however this was not observed within the cohort from Gunderson and colleagues' study[46]. The low retainment rate (9%) following 10 years of follow-up identified is an interesting yet promising finding compared to the higher figures identified by other cohorts[38, 45, 47]. This however may be explained by the greater proportion of outpatients included in Gunderson and colleagues'[46] study compared to other cohorts which have only included an inpatient sample[38, 45, 47]. Differences between individuals initially treated within an inpatient or outpatient setting have not been examined within longitudinal studies, although it may be assumed that individuals in outpatient settings are less symptomatic compared to those within inpatient settings. Recent treatment guidelines endorse the treatment of individuals with BPD best occurs within the community[14, 15], thus further investigation is required.

Greater Understanding of Personal Recovery in BPD is Required

The strong focus in the literature on clinical remission, rather than personal recovery, is not a surprising finding, given the severity of the disorder and the significant impact BPD can have on quality of life. This coincides with the increasing number of psychotherapeutic interventions designed specifically for the treatment of BPD. A focus on improving clinical characteristics of BPD to facilitate change was identified within qualitative studies. Although only one study[22] identified specific treatments engaged in by participants, all qualitative studies included treatment seeking participants. Thus, themes reported in qualitative studies may be to a degree influenced by the theoretical orientation of treatments received. The alignment of treatment targets with personal recovery goals however, requires further investigation where discrepancies were identified in some studies. Katsakou and colleagues[22] identified that psychotherapeutic interventions did not address all treatment goals consumers had for recovery. Hence, it is suggested that the target goals of specific interventions designed for the treatment of BPD may not fully reflect the treatment goals of consumers. Developing insight into consumer goals and whether they are aligned to the goals predetermined by researchers will assist to understanding whether interventions need to be adapted to better accommodate consumers throughout treatment and assist in developing mental health services that are recovery-oriented. Findings of the current review suggest that functioning of consumers with BPD improve over an extended period of time. However, the average level of functioning indicates that consumers have ongoing difficulties with functioning, with approximately 65% of consumers not

engaged in a vocation during the follow-up period. This is consistent with previous research examining vocational functioning in individuals with BPD[59], however research has noted higher rates of psychosocial functioning is observed compared to vocational functioning[49, 59]. Although low rates of vocational engagement were identified in the review, qualitative studies identified a strong desire from consumers for meaningful roles and employment, suggesting that despite intentions, symptomatic remission may not be sufficient to allow consumers engage in their desired level of vocation.

The desire for vocational engagement however, was not identified as the only facilitator of recovery where the completion of day to day activities contributed to a consumer's willingness to engage in the recovery process. This not only exemplifies the personalised nature of recovery journey but also indicates that the stage of recovery may influence a consumer's perceived ability to engage in vocation and activities. To strengthen the level of societal participation, recommendations for the integration of psychiatric rehabilitation as part of the treatment of BPD have been suggested in the literature[49, 59, 60]. However, little is known about the stages of recovery from BPD and whether differing recovery stages require adapted approaches to better suit the consumer. Greater consideration of the association between a consumer's self-rated stage of recovery and their narratives may provide insight into the needs of individuals at different stages of recovery and also how psychiatric rehabilitation services can incorporate this into care.

Consumer Conceptualisations of Recovery Requires Further Investigation

Findings from the qualitative studies indicate that the word 'recovery' may not fully encapsulate the experiences of consumers with BPD. Two papers included in the review[18, 22] discuss the concerns of consumers; however do not propose a more holistic conceptualisation. This is a unique finding as previous research examining recovery in other mental illnesses has readily used the term to describe the consumer experience[61, 62].

The shift away from understanding recovery purely from a clinical perspective was highlighted in both longitudinal and qualitative studies, where symptom management and reduction was not identified as a consumer's highest priority. The engagement in vocation and activities was prioritised by consumers, further suggesting that clinically focused conceptualisations of recovery may not describe the recovery experience. This also reflects differences between the definition of clinical and personal recovery and indicates that these notions of recovery may be interconnected. This is consistent with suggestions that clinical and personal recovery is complementary of each other[4, 62]. Although a number of conceptual frameworks describing personal recovery have been posited in the literature (see [17, 63] for review), limited research in the literature has examined how clinical recovery fits into the conceptual frameworks of recovery.

Conceptualising recovery in light of consumer views may be a more holistic approach to understanding outcomes in BPD. This can include shifting away from solely focusing upon the acute clinical symptoms by incorporating individualised assessments in determining outcomes. Gaining understanding of consumer goals for treatment and recovery and incorporating their views into clinical practice and psychotherapy research may assist to personalise interventions to suit individual consumers.

Perspectives of Family and Carers are Needed in the Literature

At present, no studies have examined the perspectives of family and carers on recovery. Considering the increased caring role family and carers have taken on since the

deinstitutionalisation of mental health services overcoming this limitation is important, especially given the burden of caring reported in recent work[64–67]. Differences between carers and consumers over the factors attributed to recovery have also emerged[68], however these perspectives have not been specifically applied to BPD and limited understanding into the actions or strategies adopted by family and carers to promote recovery in their loved ones on a day to day basis have been examined in the literature. Understanding the facilitators and hindrances associated with recovery through multiple perspectives may lead to the strengthening or adaptation of actions and strategies to facilitate recovery.

Similarly the perspectives of mental health clinicians on the recovery journey in BPD were also absent. Misunderstandings surrounding what constitutes as recovery has also been identified as a barrier to clinicians promoting recovery[69]. Differences in understanding may have detrimental effects on therapeutic alliance. Gaining a clear understanding into how clinicians perceive recovery and whether these perceptions align to consumers' perspectives may assist with strengthening the therapeutic alliance.

Strengths and Limitations of the Review

Although only one researcher screened and assessed articles for review inclusion, the greater focus on the clinical aspects of recovery in BPD identified by the systematic search limits has the capacity to provide a balanced review of this area. The absence of studies meant a holistic view of the recovery process from the perspectives of consumers can only be gleaned from what is available. Despite similarities in the diagnostic criterion used (eg DIB, DSM-III, DSM-IV and Gunderson & Kolb's[50] criteria), each criteria have different definitions for what is considered remission or relapse. Skewed results may result and these differences may have an impact upon understanding patient outcomes between studies.

The exclusion of the forensic settings from this study may have had the effect of reducing the opportunity to include males with BPD in this review, since it is known that such settings have a high proportion of males with BPD. The specific impact of incarceration or other forensic involvement on recovery from BPD is unknown. We recommend that future studies specifically study this group, in order to progress our understanding of recovery from those who have the disorder. Such work may also help to understand the effect on BPD recovery from varying rates and durations of incarceration or involvement in the criminal justice system.

The review excluded studies with a follow-up period of less than five years and all intervention related studies. This resulted in the exclusion of studies examining the effectiveness of treatments, as these would provide a description of the treatment effects and mechanisms driving change rather than long-term outcomes. The types of treatments received by consumers however, may influence the factors associated with recovery identified from both the longitudinal and qualitative studies. Future research could identify whether a relationship between the types of psychotherapeutic interventions received with the types of treatment goals consumers have for recovery.

Conclusion

Despite increasing evidence that symptomatic remission from BPD is possible, the focus on traditional understandings of recovery has been questioned by consumers, where a more holistic approach has been called for. It may be that a better understanding of recovery includes maintaining sub-threshold symptom expression, engaging in vocational activities that are personally meaningful, and sustaining close personal relationships. Further research is needed to define personal definitions of recovery from BPD. This is in contrast to traditional notions of recovery (as absence of symptoms) and acknowledges that difficulties in functioning may

persist, as noted by findings reviewed here. Additionally, the increasing role of a consumer's support network in contributing to their recovery has been acknowledged, however this has not translated into the research literature. Understanding of the views, perspectives and difficulties clinicians and family and carers may have towards recovery in BPD will assist in understanding interactions between these groups and to identify implications for comprehensive treatment.

Supporting Information

S1 Table. PRISMA checklist.
(DOCX)

S2 Table. Quality assessment of quantitative studies using Lupppino and colleagues[29] criteria.
(DOCX)

S3 Table. Quality assessment of qualitative studies using Kuper, Lingard and Levison[32] and Daly and colleagues' heirarchy of evidence[33].
(DOCX)

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APPENDIX J: Quality Assessment of Quantitative Studies (Phase One)

	Gunderson et al (2011)	Links et al (1995)	Links et al (1998)	McGlashan (1986)	McGlashan (1985)	Paris et al (1987)	Paris et al (2001)	Plakun et al (1985)	Plakun (1991)	Pope et al (1983)	Stone et al (1987)	Stone (1990)	Zanarini et al (2003)	Zanarini et al (2006)	Zanarini et al (2010)	Zanarini et al (2012)
Study Population																
A Is the inclusion criteria/sampling procedure of the cohort described?	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
B Is the characteristics of the sample described?	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
C Is the inclusion/exclusion criteria described?	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Follow-up																
D Are participants followed up for at least an average of 5 years?	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Baseline Responses																
E Is the studied population ≥ 75% of originally selected population?	+	+	+	+	+	-	-	-	-	+	+	+	+	+	+	+
F Is there information about responders and non-responders?	-	+	+	+	+	+	+	+	-	+	+	+	+	+	+	+
Follow-up Responses																
G Is the number of participants lost to follow-up ≤ 20% of baseline sample?	-	-	-	-	-	-	-	-	-	+	+	+	+	+	+	+
H Is there information about responders and non-responders?	-	+	+	+	+	+	+	+	+	+	-	+	+	+	+	+
Measurements																
I Are the assessments for Borderline Personality Disorder diagnosis based on validated clinical assessment tools?	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
J Are the assessments for Borderline Personality Disorder clinical diagnosis based on a clinical interview?	+	+	+	-	-	-	-	-	-	-	-	-	+	+	+	+
Total	6/10	9/10	9/10	7/10	7/10	7/10	7/10	7/10	6/10	9/10	8/10	9/10	10/10	10/10	10/10	10/10

APPENDIX K: Quality Assessment of Qualitative Studies (Phase One)

Source	Data analysis method	Was what the researchers did clear?	Was the sample appropriate for the study?	Was the data collected appropriately?	Was the data analysed appropriately?	Are the results transferable?	Are ethical issues considered?	Daly et al (2007) hierarchy of evidence
Holm & Severinsson (2011)	Thematic analysis	VG	A	VG	VG	A	VG	Conceptual Study
Katsakou et al (2012)	Grounded theory and thematic analysis	VG	VG	VG	VG	A	VG	Conceptual Study
Lariviere et al (2015)	Thematic analysis	G	A	VG	G	A	U	Descriptive Study

Note. (1) VG: Very Good; G: Good; A: Acceptable; U: Unsure; (2) Studies were required to meet four of six guidelines (ranked 'acceptable' or above) for inclusion in the study.

APPENDIX L: PRISMA Checklist (Phase One)

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5-6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4-5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	4-5, Fig 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5

Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	7
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	6-7
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	8
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	7
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	None undertaken
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	8
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	8-15
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	S1 Table, S2 Table
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Table 1
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	16-21 (No meta analysis undertaken)
Risk of bias across	22	Present results of any assessment of risk of bias across studies (see Item 15).	S1 Table,

studies			S2 Table
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	None undertaken
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	22-25
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	25-26
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	26
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Submitted to journal separately

NB: The page numbers reported in the table are reflective of the manuscript submitted for review. The table is presented to demonstrate the PRIMSA guidelines were adhered to in the review process.

APPENDIX M: Published version of manuscript presented as Chapter Four

Practitioner's Corner

What Do Individuals With Borderline Personality Disorder Want From Treatment? A Study of Self-generated Treatment and Recovery Goals

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Outcome measurement has progressed in the field of personality disorders. While the majority of trials have evaluated outcomes on the basis of symptom and diagnostic indices, what is considered a meaningful and valued outcome to individuals has seldom been investigated. Self-generated treatment goals were collected from 102 individuals seeking treatment for borderline personality disorder and independently coded by 2 raters. Responses were content-analyzed to determine the categories of goals people want for treatment. A total of 464 individual goal units across 4 main goal types emerged in the content analysis: reducing symptoms, improved well-being, better interpersonal relationships, and having a greater sense of self. Although the reduction of symptoms was the most commonly reported goal, 88.2% reported wanting better psychosocial functioning, including improvements in relationships, vocation, and self-understanding. The existence of the wide range of goals suggests that there is a need for clinicians to establish a collaborative formulation of treatment goals with individuals to ensure that treatment is personalized and meaningful.
(Journal of Psychiatric Practice 2019;25;148–155)

KEY WORDS: borderline personality disorder, treatment goals, recovery, qualitative, personalized treatment

The examination of outcomes in the field of personality disorders has progressed since the first randomized controlled trial published in 1991.[1] In a recent systematic review, 33 randomized controlled trials were identified that were designed to evaluate the efficacy of interventions for people with borderline personality disorder (BPD).[2] Specialized interventions for BPD have treatment goals that target changes in behavior, such as in dialectical behavior therapy,[1] or the specific modification of representations and understanding of self and other, for example, in schema therapy, transference focused psychotherapy, and mentalization-based treatment.[3–5] However, measures used in intervention trials usually measure only the key symptoms and service use. Consumer reports suggest that we need to go beyond symptom change[6] and measure a broader set of recovery goals. This has been supported by the literature, which has reported a disconnect between service targets and personal goals of individuals with BPD,[6] and the recognition that recovery extends beyond symptom remission.[7]

Given the international shift toward recovery-oriented mental health services and the provision of person-centered care,[8] questions remain concerning what individuals perceive to be important to them at the start of treatment. Various attempts to personalize treatment and focus on service user generated goals in other diagnoses have been made. The Camberwell Assessment of Need (CAN)[9] is one example, which measures the met and unmet needs of individuals across 22 health and social domains. The aims of the CAN diverge from conventional clinical assessment, as it differentiates between the met needs (ie, met through the provision of services) and unmet needs, which are areas identified as requiring further intervention or support. Limited research has been conducted into what individuals with BPD value. In a study examining the met and unmet

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needs of people with personality disorders, 8 key areas of unmet need were identified: "self-care, psychotic symptoms, psychological distress, risk to self, risk to others, alcohol use, sexual expression and budgeting."[10(p541)] While the majority of these unmet needs reflect the symptomatic difficulties known to be experienced by individuals with personality disorder, this finding also provides an indication of the domains that require greater investigation.

One approach to personalizing treatment and focusing on the goals generated by service users has been through understanding the target complaints of individuals at the start of therapy. Measures such as Battle et al's Target Complaints Measure[11] provide an opportunity for individuals to spontaneously formulate and identify their own goals to guide the direction of therapy. The use of personalized treatment goals has been identified as producing larger effect sizes than symptom checklists when evaluating the effectiveness of psychotherapy in clinical trials.[12] The identification of specific categories of goals that individuals value may be important in understanding treatment needs and developing new ways of personalizing treatment. The goal of this study was to examine the personally meaningful treatment goals of individuals seeking treatment for BPD.

METHODS

Study Design and Participants

This qualitative study utilized data collected from individuals who were seeking treatment for BPD at a community-based psychotherapy program. Individuals were assessed for suitability for the program and were only admitted if they were over 18 years of age and had a primary diagnosis of DSM-IV-TR BPD, diagnosed using the Structured Clinical Interview for DSM by 2 trained doctoral level clinical psychologists (SCID-I and SCID-II were used to assess diagnoses).[13,14] Individuals were excluded from the program if there was indication of substance abuse, or they met criteria for a primary diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder with psychotic features, or a history of a neurological disorder. All participants were fluent in English and gave explicit informed written consent (including consent for the audio recording of clinical assessments) following approval from the institutional review board (University of Wollongong Ethics Committee).

Procedure

Participants were entering a year-long program of treatment. Individual goals for treatment were self-generated by participants at the first assessment session, guided by using the Target Complaints Measure.[11] Goals could be both specific and more general and long-term in focus and were not delimited by clinicians in any way. The Target Complaints Measure is a semistructured clinician-guided interview, which was used as part of the intake assessment session to ascertain each participant's treatment goals or chief complaints.[11] Participants were told "I want you to tell me in your own words the most important problems that you have that you want help with to change by coming here. These are the kind of goals you might have for your treatment" as specified by the Target Complaints Measure.[11] Participants were prompted to provide up to 3 goals and to self-rate how severe these were as an issue or problem for them on a scale of 0 (not a problem/least severe issue for me) to 10 (the worst/most severe issue for me).

Data Analysis

An inductive conventional content analytic approach to understanding the goals of individuals and the development of goal categories was used. This followed a 3-step approach as described by Hsieh and Shannon.[15]

Participants' descriptions of goals were audio-recorded and transcribed verbatim. Researchers immersed themselves in the data by reading and reflecting on participant responses to gain an overall understanding. First, participant responses were tagged with codes, referred to as goal units, to accurately describe the data. Because of the recognition that multiple goals could be present within an individual goal, some goals could be represented by >1 code. Thus, although the Target Complaints Measure[11] specified up to 3 goals, some participants provided >3 goals within their descriptions. Second, similar or related codes were condensed into goal categories that allowed for both homogeneity within the group and heterogeneity between groups. Lastly, goal categories were grouped into meaningful themes to represent participant responses. The coding process was supported by the use

of the NVivo 10 software for qualitative data analysis. The data were initially independently coded and categorized by 2 researchers; this was followed by the discussion and review of codes by a third researcher who is an expert in personality disorders. The trustworthiness of the data was ensured by having consistent discussion about codes and findings emerging from the data with the wider research team to ensure that concepts were not overlooked within the data. Through multiple discussions and reviews, the coding and categorization of codes were refined. Discrepancies among the coding and the subsequent categories between researchers were discussed and resolved through consensus. Illustrative quotes of the goals were provided to support and provide evidence for the interpretations of the researchers. The researchers analyzing the data were independent from the clinicians providing psychological care to the participants.

RESULTS

Characteristics of Participants

A total of 102 consecutively recruited participants seeking treatment who met criteria for a primary DSM-IV-TR diagnosis of BPD were invited and consented to participate. All participants gave written informed consent to the study. Table 1 outlines the demographic characteristics of the participants.

Treatment Goals Identified by Participants

Overall, participants identified a total of 268 goals, with an average of 2.8 goals per participant. All participants (100%) were able to report 1 goal, 100 participants (98%) reported 2 goals, and 86 participants (84%) were able to report 3 goals. The majority of goals identified had multiple components. The goals reported were then analyzed into constituent units, for a total of 464 individual goal units (Table 2) or 4.5 goal units per participant. Reported goals could include the same individual goal unit on multiple occasions in their descriptions; however, this was only counted once. Therefore, goal units identified in Table 2 are indicative of the number of participants endorsing a specific goal unit.

TABLE 1. Characteristics of Participants (N = 102)

Characteristics	*Range*	*n (%)*
Female	—	89 (87.3)
Age [mean (SD)] (y)	18-56	29.7 (8.84)
Relationship status		
Single	—	57 (55.9)
Married	—	20 (19.6)
De-facto	—	11 (10.8)
Divorced	—	7 (6.9)
Separated	—	7 (6.9)
Years of education [mean (SD)] (y)	7.5-19	12.1 (2.58)

Findings from the content analysis reveal 4 key themes associated with treatment and personally meaningful goals for recovery. The reduction of symptoms was the most commonly reported goal by participants (n = 88, 86.3%), followed by the desire to improve well-being (n = 64, 62.7%), having better interpersonal relationships (n = 54, 52.9%), and having a greater sense of self (n = 40, 39.2%). Although reducing symptoms was the most commonly reported theme, 90 participants (88.2%) also reported at least one goal pertaining to a psychosocial goal category. Goals reported by participants were identified as not being mutually exclusive, so that achievement of goals in one area could contribute to improvements in other areas.

Goal Theme 1: Reducing Symptoms

The goal of reducing symptoms was the most commonly cited theme in the study, where reducing suicidality and impulsivity and depressive and anxiety symptoms were some of the most highly reported goal categories. Participants discussed the impact of symptoms on daily functioning and self-perceptions. *"I'd certainly like to manage my depression better, so that I don't end up back in hospital again. I'd like to be able to explore things that may be affecting me as an adult so that I can understand why I feel the way about things that don't make sense. I just want to get on with my life, be a whole person rather than be in fragments"* (Individual 5091).

The experiences of symptoms were sometimes interrelated so that the experience of depressive or anxiety symptoms corresponded with a desire to engage in self-harming behaviors or increased suicidality. The reduction of symptoms had a compounding effect on a person's ability to engage in and achieve other psychosocial goals. *"I want to be able to deal with the depression and cope with distress … I'd like to*

TABLE 2. Formulated Themes and Frequencies of Participant-generated Goals Verbalized at the Commencement of Treatment for Borderline Personality Disorder (N=102; 464 Individual Goal Units)

Formulated Theme and Goal Categories	*Participant-generated Goal Statements*	*No. Participants Endorsing the Theme (% of All Participants)*
Goal theme: reducing symptoms (5 goal categories, 17 goal units)		88 (86.3)
Suicidality and impulsivity (51 participants, 50.0%)	Self-harm behaviors/thoughts	22 (21.6)
	Suicidality	17 (16.7)
	Anger	15 (14.7)
	Drug and alcohol misuse	7 (6.9)
	Gambling urges	2 (2.0)
	Shoplifting	2 (2.0)
Depressive symptoms (42 participants, 41.2%)	Negative mood/thoughts	36 (35.3)
	Mood swings	6 (5.9)
Anxiety symptoms (40 participants, 39.2%)	General anxiety	17 (16.7)
	Posttraumatic stress/trauma	17 (16.7)
	Panic attacks	7 (6.9)
	Social anxiety	5 (4.9)
	Specific phobia	5 (4.9)
Eating-related issues (11 participants, 10.8%)	Disordered eating	7 (6.9)
	Weight loss	4 (3.9)
Transient symptoms (8 participants, 7.8%)	Dissociation	6 (5.9)
	Hallucinations	2 (2.0)
Goal theme: improving well-being (4 goal categories, 14 goal units)		64 (62.7)
Coping style (46 participants, 45.1%)	Having control over emotions	25 (24.5)
	Improve coping style	17 (16.7)
	Coping with distress/stress	15 (14.7)
	Having control over thoughts	7 (6.9)
	Improve functioning and use of skills	8 (7.8)
	General sense of control	2 (2.0)
Vocation (21 participants, 20.6%)	Engaging in paid work	9 (8.8)
	Engaging in activities	8 (7.8)
	Education	5 (4.9)
Current life situations (18 participants, 17.6%)	Solve specific life situations	14 (13.7)
	Financial situation	4 (3.9)
Physical health (9 participants, 8.8%)	Improve physical health	5 (4.9)
	Stay out of hospital	3 (2.9)
	Come off medication	1 (1.0)
Goal theme: better interpersonal relationships (4 goal categories, 14 goal units)		54 (52.9)
Interpersonal skills (23 participants, 22.5%)	Overcome my grief and loneliness	10 (9.8)
	Being assertive with others	5 (4.9)
	Trusting others	4 (3.9)
	Become independent	3 (2.9)
	Reduce abandonment fears	2 (2.0)
Improving current relationships (22 participants, 21.6%)	Relationship with my significant other	6 (5.9)
	Relationship with my friends	6 (5.9)

TABLE 2. Formulated Themes and Frequencies of Participant-generated Goals Verbalized at the Commencement of Treatment for Borderline Personality Disorder (N=102; 464 Individual Goal Units) (*continued*)

Formulated Theme and Goal Categories	*Participant-generated Goal Statements*	*No. Participants Endorsing the Theme (% of All Participants)*
	Relationship with my family	6 (5.9)
	Relationship with my mother	5 (4.9)
Connectedness	Connecting with others	12 (11.8)
(21 participants, 20.6%)	Developing relationships	7 (6.9)
	Relating to others	5 (4.9)
Parenting (8 participants, 7.8%)	Develop my parenting skills	6 (5.9)
	Have contact and a better relationship with my children	4 (3.9)
Goal theme: greater sense of self (2 goal categories, 11 goal units)		40 (39.2)
Attitudes toward self	Having self-esteem and self-worth	12 (11.8)
(27 participants, 26.5%)	Sense of self	9 (8.8)
	Having self-confidence	4 (3.9)
	Become self-accepting	3 (2.9)
	Improve self-image and reduce perfectionism	3 (2.9)
Personal awareness	Understanding myself	10 (9.8)
(23 participants, 22.5%)	Develop my goals and motivation	8 (7.8)
	Identifying my vulnerabilities	5 (4.9)
	Reducing feelings of emptiness	4 (3.9)
	Having a sense of purpose	2 (2.0)
	Having my own opinions	2 (2.0)

get to a point where I can go back to do some study or do some work" (Individual 3054).

Goal Theme 2: Improving Well-being

Goals pertaining to improving well-being were global in nature, and individual differences contributed to the heterogeneity of the goals. The desire to improve coping style was one of the most highly reported goal categories by participants and widely reflected the overall desire to improve symptomatically. The ability to effectively manage emotions and thoughts was believed to contribute to improved quality of life and emotional experience. *"To learn how to control the fuzziness that leads to those instances and slowly reducing the want, need and the action of self-harm"* (Individual 5086). Goals associated with improving current life situations and financial situation were also at times interconnected with symptoms and interpersonal relationships. Life situations mentioned were broad and included court cases, assault, divorce, and the loss of a child. *"At the moment, the involvement of court case for sexual assault is very stressful … It has restricted parts of my life, through avoiding people and avoiding relationships. Want to get on with life and put it behind me"* (Individual 3051). Despite goals to improve life situations, one participant articulated that these may be considered *"general life problems"* (Individual 5076), highlighting the common experiences of individuals.

Vocational pursuits such as engagement in paid work and education were valued goals. Despite the desire to be connected with society, the emotional intensity experienced by participants was identified as a barrier. *"Being employable, but when you look at my CV, it's like what have you been doing all these years? Getting a part-time job is really important. If I took on a full-time position, I would let down my employer and myself because it has been a few years*

since I have been in work" (Individual 5100). Yet, it was recognized that participation in a structured vocation may not be suitable for all individuals, so that assisting individuals to take part in personally meaningful activities would be a valued target of treatment. *"I really want to do dancing. Dancing used to really help me … I think it is teaching myself to go there and not matter whether I will be put down for it"* (Individual 5151).

Goal Theme 3: Better Interpersonal Relationships

Having better interpersonal relationships was another key theme associated with developing a sense of connectedness with others, improving current relationships, and developing interpersonal skills. Connectedness was described by participants as being on a continuum including developing relationships, connecting with others, and relating to others. *"Just being able to feel like I fit somewhere, I feel like I don't fit. I'm too scared to go out and meet new people … It is a big problem cause I don't do anything"* (Individual 5106).

Difficulty relating to others was acknowledged, along with the goal that it could be improved through a process of developing better communication, engagement, and understanding of others. The reported goal of developing and improving interpersonal skills reflected the need to overcome grief and loneliness, to be more assertive, and to establish trust with others to more effectively initiate or engage in relationships. *"Be able to go with my own judgement or my own decision, instead of running to my father all the time and his opinion—like decision making and assertiveness. I don't trust my own judgement and I am not very assertive either"* (Individual 5078). Relationships were mainly discussed by participants in the context of their significant others, friends, family, and mothers. Participants also identified specific goals related to improving parenting capacity.

Goal Theme 4: Greater Sense of Self

The theme of developing a greater sense of self was associated with improving attitudes toward self and increasing personal awareness. The goal of increasing personal awareness was expressed as achievable through developing greater self-understanding and being able to conceive of what might be a meaningful life direction or goal, and to have motivation to move in that direction. *"Be more of a whole person … learning some tools that will help me be motivated to get out and do things and enjoy life instead of dragging myself through it, all the time"* (Individual 5091).

Some participants broadly discussed goals to "get to know who I am," while others discussed a desire to shift away from a "victim persona" developed from experiences of trauma and to no longer be viewed only through the lens of their BPD diagnosis. *"I have childhood issues and I'm hanging onto them. I'm dealing with them really well … but still need help to deal with some of those issues, how to not be a victim"* (Individual 3054). Goals pertaining to the development of self-esteem and self-worth were discussed, as were the negative consequences of poor self-esteem and self-worth *"If I consciously self-harm, it is because of my self-esteem. I just hate myself"* (Individual 5090).

Some participants recognized that improving self-esteem may be an ongoing journey, and that a person's attitude toward himself or herself is inextricably linked with increasing personal awareness. The ability to separate oneself from others in order to develop a sense of who one is and a sense of genuineness was also identified by some participants. *"Getting to know me … I want to be more consistent. I've gotten to the point where I push people away because I can't be me and I am sort of resenting them for it, even if they are not doing it"* (Individual 5113).

DISCUSSION

This study explored the views of individuals seeking treatment for BPD on their personally meaningful goals for treatment. Participants identified goals in 4 main categories: reducing symptoms, improving well-being, having better interpersonal relationships, and having a greater sense of self. Personally meaningful treatment goals identified in this study extend beyond the reduction of symptoms to include those of a psychosocial nature. This finding supports calls to expand outcome measures used to monitor progress by including aspects that are global in nature, such as subjective well-being and the views of individuals seeking treatment.[16,17] The goal themes identified in this study were consistent with research examining the lived experience of individuals with personality disorders[6,18,19] and reflected some of the domains present in the CAN.[9] Domains of psychopathology in BPD were also reflected in the identified goals,[20] including

difficulties in relational functioning, emotion dysregulation, and understanding of self and others. However, the identified goal themes and categories expand on the work to date in the literature by providing greater insights into the specific aspects that may be important to individuals that could be potentially targeted during treatment.

The identification of symptom reduction as the most cited theme was not surprising given the severe nature of BPD and that individuals were at the start of treatment. Interestingly, studies of the lived experience of personality disorders have conceptualized recovery as the reconciliation of self and other representations through the development of a sense of self that could be achieved through the engagement of interpersonal relationships and the community.[6,21] Although these themes are reflected in the findings from our study, fewer than half of the participants reported goals associated with developing a greater sense of self. This may be associated with the sample being at the start of treatment, in contrast to other studies where participants were engaging in a specialist intervention and therefore were more aware of their underlying difficulties. This finding may also reflect the shifting nature of treatment goals and suggest that routine monitoring of goals may be required.

The treatment goals that were reported were not mutually exclusive, so that participants believed that improvements in one goal would contribute to the achievement of other goals. This suggests that there may be multiple processes and challenges involved in achieving desired recovery outcomes in a personally meaningful manner. Although the identification of these processes and challenges were beyond the scope of this study, understanding these will have implications for clinical practice and can provide guidance for the development of recovery-oriented mental health services for BPD.

Implications for Clinical Practice

The narrow treatment targets of interventions for BPD have been reported as a limitation to care by individuals with BPD.[6] Although this study identified similarities between individual treatment goals and the typical targets of interventions, some identified goal categories and units did reflect that a wider focus may not be captured in psychotherapeutic interventions and treatment manuals for BPD. Given the findings reported here, there is room for treatment manuals to focus more broadly on goals identified by individuals. Having broader treatment targets may also have the effect of generating greater motivation for behavioral change and improving treatment engagement. In addition, the therapeutic alliance between clinicians and individuals could also profit from greater awareness of individual goals.

The development of new methods of integrating existing psychotherapeutic evidence-based approaches with psychosocial interventions may be important in assisting individuals with BPD to achieve their desired outcomes.[22] The findings from this study provide a basis for understanding areas of importance to individuals with BPD. Evidence-based social interventions and psychosocial rehabilitation interventions such as illness management and recovery,[23] assertive community treatment,[24] or individual placement and support[25] may help support individuals with BPD in achieving goals that extend beyond the scope of the current manualized interventions with an evidence base. In addition, developing the capacity of individuals with lived experience to become peer support workers may also present a unique opportunity for individuals with similar experiences to learn from each other.[26]

The development of enhanced therapeutic interventions that target specific goals of interest to individuals with BPD may also be relevant. One recent example of such an intervention pertains to improving the parenting capacity of individuals with BPD who are parents.[27] Continual evaluation of the integration of these interventions with evidence-based interventions should be completed using multiple measures and methodologies.

Limitations and Future Research

Treatment goals reported by participants in our study were framed in a clinically oriented manner, so that goals predominantly focused on the symptoms and problems participants wanted to overcome. Although this can be attributed to the context in which goals were formulated, the identified goals may also be reflective of individuals who are at the start of their recovery journey. The goals, however, provide a good indicator of the valued outcomes through the perspectives of individuals seeking treatment. The wide range of individual goal units (N = 464) identified is also indicative of the personal nature of treatment goals and the need for mental health clinicians to ask individuals what

their goals are for treatment, particularly given the links between goal consensus, collaboration, and attainment.[28,29] Goals for treatment and recovery are not static. This is reflected in the nonlinear trajectory of recovery.[30] More research examining changes in goal content longitudinally may provide a more nuanced understanding of the differences between individuals who may be at different stages of their recovery and whether treatments received are assisting individuals to attain their goals.

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APPENDIX N: Additional Illustrative Quotes from Phase Three

Superordinate Theme	Sub-theme	Illustrative Quote
Recovery as self-management	**Self-management general**	‘I don't think one can recover per se. I believe one gets better at BPD management over time’ (JTR067) ‘Recovery is an ongoing process in my opinion. Just as personal growth does not have a definite conclusion, BPD recovery does not have a finite end point. I consider myself to have learned to better manage behaviours and consequently I have a better quality of life. However, the process is ongoing. Just because my behaviours have improved, doesn't mean that I'm finished or "cured"’ (JTR111) ‘I don't like the word recovery personally. I don't believe I will ever be ‘recovered’ and know it sounds like I have no hope for my future but realistically, I believe this isn't something I ‘cure’ but something I can learn to manage’ (JTR482)

	Improving and living well with symptoms	‘I see recovery more as symptom management and streamlined integration back into functioning society. In my opinion my BPD is an intrinsic feature of my psyche.’ (JTR102) ‘To me recovery would be living a life that is it not ruled by my condition, where my symptoms are either completely non-existent or there were none at all. A huge factor would be feeling that it had nonnegative hold over my life’ (JTR050) ‘Being in a place where I am able to regulate my emotions in a more proactive ways, rather than taking the feelings of guilt and shame just to name a few sticky emotions and thinking that I deserved to be punished. This led me to a dark place of self-harm and wanting to die on a continuous loop. The ability to change that loop and replace them with feelings of hope and that I am worthy of feeling safe again. The ongoing use of mindfulness which helps me to live in the moment and true to myself. To decrease those thoughts and feelings, such as feeling unsafe, vulnerable and that people aren’t understanding that awful pain faced every day. Being able to let go of my past childhood abuse and other sexual assaults, as well as the feelings that surrounded having a mother who was unwell with her own mental health issues. But learning how to change my own behaviours, reactions and seeing these from third person has helped to

		make the relationship more pleasant and not just with my mum but the other friends and family. To me though recovery will always be on an ongoing journey.' (JTR059) 'To be free of the scenario where you find yourself at the end of your emotional tether and about to plunge into that horrid abyss of darkness and the associated rage of madness.' (JTR116) 'For me, it isn't recovery from BPD, it's recovery within BPD. My personality disorder will always be a part of me even if I learn to control it because it is my personality. However, I know that it won't always be like this; I know that I can learn to identify every thought as being either rational or irrational and I can learn to only act upon the rational thoughts. I define my personal recovery as being as functional as someone with no mental illness. Recovery doesn't mean being cured, it means being able to go to all my classes, getting a job, practicing at least minimal self-care, having stable and long-term relationships, and not using destructive behaviours to deal with the emotions I can't express. The first step to that

		recovery is accepting that I need help and I am worthy of that help because I am not a lost cause' (JTR174) 'I define recovery as being able to effectively tolerate my own emotions. Recovery is being able to perform my own self-care in order to stop myself getting mentally sicker. Being able to deal with personal relationships effectively. Seeing a therapist just to check in. Taking medication regularly' (JTR194) 'I hope to be able to have a healthy, stable romantic relationship one day. I feel like my emotions are a part of me and I don't necessarily want to numb them but to "recover" would mean that they would not be as disruptive in my daily life' (JTR143) 'Having a life that doesn't totally spin out all the time due to impulsivity & intensity: keeping a job / doing ok in school, keeping friends, having more good days than bad ones, or at least enough to make it worth it' (JTR189)

		‘Being able to enjoy relationships without fear, being able to live a productive life and have meaningful relationships with family and loved ones and being able to manage interpersonal stressors, especially at work’ (JTR060) ‘Being able to live a healthy and successful life with the same opportunities and abilities as most other people, for example being able to keep a job, friendships, stable accommodation. Being able to manage emotions in a healthy way through supports and self-understanding’ (JTR233) ‘No longer dealing with the emotional roller coaster called severe mood swings’ (JTR289) ‘While the symptoms and problems associated with the disorder may never go away, I believe recovery is the ability to identify and control the negative impulses and rationalisations of the disorder. Essentially, learning to live with it using positive and constructive methods of coping. I have all nine requirements needed for a diagnosis along with all of the other symptoms usually listed as less common so I don't truly believe I will ever live go into

		complete remission from the disorder. I believe it is possible to lead a positive and happy life while managing my symptoms and behaviours' (JTR298) 'Being able to live a contributory life. Able to manage symptoms and apply self-care techniques when required. Being able to recognise when self-care is required' (JTR355) 'Thriving and living a fulfilling life incorporating BPD into it' (JTR336) 'I was initially hoping that recovery meant a cure, that once I'd completed therapy it would all be over… Now I'd just be happy if I could control the rapid emotional cycling that sees me go from high conquering the world to low suicidal feelings in the space of 20 minutes. So recovery is a fluid term but my definition of it is that at the end of therapy I no longer fit the criteria for BPD and that my emotional instability is controlled' (JTR397) 'Recovery for me is not feeling like I am powerless over my own emotions all the time. I don't see 'recovery' as the same thing as 'cured'. I don't believe my emotional, thought and behaviour

		patterns will necessarily ever go away or change completely but I think that having more control over them and understanding them will lead to recovery' (JTR492)
	Amelioration of specific symptoms (such as self-harm and suicidal ideation)	'No more suicidal thinking.' (JTR575) 'Not wanting to kill myself when people I like are happy for reasons that don't directly involve me' (JTR114) 'All self-harming & suicidal behaviours ceased' (JTR118) 'Feeling worthy, accepted and able to cope without an insatiable negative conversation between my heart and head. Healthy relationship between those I am closest to. Not having incessant thoughts of suicide' (JTR224) 'Accepting myself, no more self-hatred and self-harming behaviour, suicidal impulses, being able to cope with stress' (JTR340) 'Stop self-harming and feeling so suicidal' (JTR395)

		‘Being like everyone else. Having normal mood swings. Being tolerant. No self-harm or any other dangerous/harmful things’ (JTR409) ‘Recovery to me, is a place where I don't have self-harm thoughts crossing my mind’ (JTR470)
	No longer meeting criteria	‘To me, ‘recovery’ occurs when a person no longer meets the minimum criteria to be diagnosed with Borderline Personality Disorder. That is to say, their behaviour and thinking patterns have changed so drastically that they meet fewer than the number of criteria required.’ (JTR117) ‘I define my own recovery as that my symptoms and maladaptive behaviours are in remission to the point that I am able to live a relatively stable and productive life, working part time and not having any significant relapse that leads to hospital (related to BPD) in a 2 year period’ (JTR031)

		‘Sustained relationships and full time employment with a remission of the majority of BPD symptoms’ (JTR184) ‘No longer meeting the diagnostic criteria for the disorder’ (JTR226) ‘Personally, having a life without symptoms of BPD and having a worthy life that is fulfilling. It is also clinical recovery - meeting no more than 2 of the criteria for more than two years, and being functional; healthy, mutual relationships, a life with purpose, stable work or study, recognised, achieved goals. Recovery from BPD is different to other illnesses in that when we achieve recovery (no longer have BPD), we will never have BPD again. In recovery, the brain changes, the personality changes and the person's identity changes. It is not managing BPD, it is being the same as everyone else without BPD’ (JTR280) ‘A combination of no longer meeting diagnostic criteria, and the subjective experience of ‘wellness’’ (JTR523)

	Comfort and acceptance of oneself	‘I guess recovery is where you are at a point of being comfortable with who you are and your place in life’ (JTR003) ‘Feeling settled in yourself’ (JTR048) ‘I don't define it a behavioural reduction. To me it has to be more internal - inner contentment and a desire to continue living a life that feels worth living’ (JTR137) ‘I define recovery from BPD as being able to look in the mirror and be happy with the face that looks back at me. I am now able to realise when I act a certain way (how someone without BPD wouldn't normally act) and I'm able to transition my way of thinking to a more logical solution. I define recovery by being able to help someone who has BPD by explaining how I recovered, and actually believing in what I'm saying. I no longer turn to self-harm, suicidal tendencies, or other harmful behaviours as either a way to cope or a way to manipulate’ (JTR228) ‘Living as opposed to just surviving. Coming to truly love myself and regaining enough self-esteem and self-confidence that I can get angry when people don't respect me and my

		boundaries (because I feel I deserve better) and assert myself. Stop feeling like everyone else's needs are more important than my own, and stop feeling ashamed or 'selfish' for putting me first. Stop abandoning myself! I truly believe at the core of BPD is the sense that we are fundamentally bad and worthless. Recovery for me also means being more forgiving to myself and allowing myself to make mistakes. I am not perfect, none of us are perfect, but there have been times when I have let something slip and it has then been the catalyst for so much shame I've tried to kill myself. Recovery for me means seeing myself as an equal to others. Maybe it's not so much that I put people on a pedestal but I put myself in a pit, so of course other people are going to seem grand. I know I am recovering when I start to treat myself like I would treat a good friend, and view myself as highly as I view counsellors' (JTR246) 'Being able to see a future for myself without doubt, loving myself for who I am and finding balance with my emotions' (JTR316) 'To be able to relax within myself and be content with my own company' (JTR456)

	Use of Coping Strategies	‘Recovery is a long term objective that can only be achieved by constant use of DBT skills to help minimise emotional vulnerability and radically accept the things we cannot change’ (JTR044) ‘Effectively using strategies to cope with the symptoms of BPD and being able to function effectively as part of society.’ (JTR101) ‘Recovery is having the tools/skills you need to process overwhelming emotional responses. Recovery is being able to react to situations in a healthier way than ‘”fight or flight"’ (JTR121) ‘Learning how to take care of myself through DBT. Persisting to use my skills to make each moment better than the last, my recovery is up to me’ (JTR239) ‘The ability to use your skills to deal with a change in emotion or situation in which you struggle’ (JTR241) ‘Applying DBT skills successfully in every day experiences’ (JTR292)

		‘The ability to live your life with the tools required to manage the symptoms of BPD’ (JTR496)
Description of Recovery	**Fluctuating**	‘No longer showing any symptoms, feeling in control of your life and thoughts. Not relying on medication to enable you to do this. I have managed this in the past, but recently I am experiencing a relapse’ (JTR037) ‘Recovery is a journey without a specific end point, I could at some point begin to experience more severe symptoms again, though that doesn't equate to failure, just a setback that I can work through’ (JTR162) ‘Bumpy & exhausting. So many ups &downs that I feel hopeless & empty.’ (JTR251) ‘You'll always be in recovery, the longer you go without slipping the prouder you'll be. Two years now for me without any episodes’ (JTR499)

	Ongoing	‘Recovery to me is being able to handle my feelings. I have felt like I’m on the road to recovery before, but never felt fully recovered yet’ (JTR018) ‘It’s not easy, it’s being an uphill battle and I’m still very much going through the ups and downs of recovery but I keep pushing on because I know one day all this hardship and hard work will be worth it’ (JTR009) ‘I believe I'm actually in a state of recovery, but like an alcoholic, it's never over. It's a constant struggle, constant awareness, and constant mindfulness… Just as a person on heart medication needs their meds, so do I’ (JTR309) ‘Still struggling. A life time illness’ (JTR477) ‘A never ending journey. I am forever finding new ways to cope. I suppose that is what life is about though’ (JTR562)

Recovery as not possible or unsure of definition	**Not possible**	‘I don’t believe it is possible’ (JTR034) ‘I do not believe I can recover. I feel as if I even have control over my psychiatrist’s view of me and if I fear he is in control or knows too much about me I cease appointments. I don’t know why’ (JTR053) ‘There is no recovery’ (JTR126) ‘I have good days, I have bad days. I don’t feel like it’s something I can recover from’ (JTR166) ‘You never recover. You stumble and struggle your whole life’ (JTR240) ‘I don't know that there is such a thing. For me, I feel like I have been this way my entire life. Now that I'm in therapy they're asking me to change who I am and how I approach life. I'm 60. I've been shooting from the hip my entire life. I thought that's what everybody did. It feels to me hopeless at times because I've been told that the average recovery takes 10 years. I'm not really sure I know what recovery looks like anymore’ (JTR243)

		‘There is no way to recover’ (JTR256) ‘In short, it is non-existent. There is no such thing as 100% recovery and in terms of how health professionals dealt with it/me, it was more so ‘a case of me being processed through the health system.’ In/out in minimum time, with very few consultations (all of which had severe time constraints). The consultations all seemed to be about pushing drugs as a solution, rather than being able to talk how I was feeling’ (JTR277) ‘Long and painful. Always conflicting. It’s like being a human contradiction and you just never know how it’s going to turn, how you're reacting or going to react, sometimes you don't even know if it’s because of you or if it’s your disorder. I don't even think recovery is possible to be truly honest’ (JTR301) ‘Recovery doesn't exist. I will never be able to recover in the sense that I will never not endure BPD symptoms’ (JTR527)

	Unsure of recovery definition	‘Not sure how I would define recovery as still in the process’ (JTR089) ‘I don't think there's such thing as recovery, because I don't think it's a real disorder. I think they give us the diagnosis because they can't decide what's really wrong with us. I think it's just a collection of personality traits that can change over time, so changing those traits can be seen as ‘recovery’’ (JTR207). ‘It is for me a daily struggle, I have had CBT and been seen by psychiatrists but they haven't helped much. I am at presently on anti-depressants and been left to my own devices as the doctors are saying as I can’t go to group therapies, there is nothing else they can do’ (JTR419) ‘I still don't know’ (JTR378)

APPENDIX O: Published Version of Manuscript Presented as Chapter Six

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Borderline Personality Disorder and Emotion Dysregulation

RESEARCH ARTICLE Open Access

The lived experience of recovery in borderline personality disorder: a qualitative study

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Abstract

Background: The concept of recovery in borderline personality disorder (BPD) is not well defined. Whilst clinical approaches emphasise symptom reduction and functioning, consumers advocate for a holistic approach. The consumer perspective on recovery and comparisons of individuals at varying stages have been minimally explored.

Method: Fourteen narratives of a community sample of adult women with a self-reported diagnosis of BPD, were analysed using qualitative interpretative phenomenological analysis to understand recovery experiences. Individuals were at opposite ends of the recovery continuum (seven recovered and seven not recovered).

Results: Recovery in BPD occurred across three stages and involved four processes. Stages included; 1) being stuck, 2) diagnosis, and 3) improving experience. Processes included; 1) hope, 2) active engagement in the recovery journey, 3) engagement with treatment services, and 4) engaging in meaningful activities and relationships. Differences between individuals in the recovered and not recovered group were prevalent in the improving experience stage.

Conclusion: Recovery in BPD is a non-linear, ongoing process, facilitated by the interaction between stages and processes. Whilst clinical aspects are targets of specialist interventions, greater emphasis on fostering individual motivation, hope, engagement in relationships, activities, and treatment, may be required within clinical practice for a holistic recovery approach.

Keywords: Borderline personality disorder, Recovery, Lived experience, Qualitative

Background

Recovery in borderline personality disorder (BPD) has predominantly been viewed in the context of symptom improvement and no longer meeting diagnostic criteria. Longitudinal studies have demonstrated that symptom remission is a common occurrence, with remission rates ranging between 33 and 99% [1]. Personal recovery however, adopts a holistic stance and views recovery as a process rather than a fixed outcome [2, 3]. Conceptual frameworks of personal recovery have synthesised the stages across the transtheoretical model of change, and processes into the CHIME framework (connectedness, hope, identity, meaning and empowerment) [4]. The application of personal recovery to individuals with BPD requires further exploration [5].

Qualitative studies examining the experience of individuals with personality disorder describe recovery as involving the reconciliation of self and other representations, fostered through interpersonal relationships and integration within the community [6, 7]. These views were similarly identified by Castillo and colleagues [8] who described recovery as a hierarchical process, starting from the development of healthy attachment patterns, progressing to a state of transitional recovery. This process encompassed stages including, the sense of belonging, and development of hope, goals, identity and roles [8]. These stages were similar to the personal goals by Katsakou and colleagues [2], which included aspects associated with regulating emotions and other symptoms. These findings were further confirmed in a study of treatment goals of

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individuals seeking treatment for BPD, where goals were identified to extend beyond the reduction of symptoms and included improving relationships, developing a sense a self and improving one's sense of wellbeing [9]. Whilst these findings indicate the treatment targets of manualised interventions may be narrow, there are innate difficulties in understanding recovery in personality disorders [7], given the similarities between clinical phenomenology and domains of personal recovery. The current changes to the conceptualisation of personality disorder from a categorical to dimensional approach, focusing upon individual traits, severity, and functioning, provides an opportunity to more fully integrate individual perspectives into treatment [10].

The perspectives of individuals accessing specialist treatment have been well represented within the literature. While important, a broader approach to include individuals who do not access specialist services, such as who have difficulty accessing services or no longer require services may provide a more representative view. This coincides with calls to further understanding the experiences of people who are at the opposite ends of recovery [11]. Therefore, this study aims to understand the experience and conceptualisation of recovery in individuals with BPD who are at varying stages of the recovery process. Comparisons between individuals in the recovered and not recovered groups were made to illustrate differences.

Method

Participants and inclusion

Individuals were initially recruited to take part in an online survey, via mental health organisations and social media, adapting methods used by previous studies of experience in personality disorder [12]. The study's inclusion criteria was based on the recognition in the wider literature that recovery may occur across stages and is fluctuating in nature (Andresen et al., 2003). A longitudinal study of individuals with schizophrenia identified that half the sample did not progress past the first stage ('overwhelmed by the disability'), and no individuals attained the final stage of recovery ('living beyond the disability') within the two-year follow-up period [11]. Findings from a study examining recovery in BPD similarly identified the final stage ('recovered') to be more uncertain [2]. Therefore, the perspectives of individuals at the extreme ends may be important to understand in order to capture what the recovery spectrum in BPD may entail.

Following completion of an online survey, researchers grouped individuals into one of four groups identified by recovery and diagnostic status. Recovery status was obtained through asking individuals to define recovery in BPD and identification with their personal definition. Diagnostic status was determined through the McLean Screening Instrument for Borderline Personality Disorder (MSI-BPD) [13]. The MSI-BPD is a 10-item self-report screening measure, where a score of 7 or greater indicates the high likelihood of meeting DSM-5 criteria for BPD. The MSI-BPD has good psychometric properties with high sensitivity (0.81), specificity (0.85) and reliability (alpha = 0.74) [13]. The narratives of individuals who self-identified with being recovered and no longer met criteria for BPD (recovered group), and individuals who did not self-identify with being recovered and met criteria for BPD (not recovered group) were included in the study. Individuals were further matched on age, gender, and treatment history. Narratives were included into the study until thematic saturation was reached. This resulted in the inclusion of 14 individual narratives ($n = 7$ recovered group and $n = 7$ not recovered group). The study was approved by the University of Wollongong Social Sciences Human Research Ethics Committee (HE16/215) and all individuals provided informed consent.

Data analysis

Semi-structured interviews following a topic guide were conducted. The guide provided general prompts for the interviewer and was refined following consultation with a consumer advisory committee (Additional file 1). The interviewer asked individuals to describe their first experiences with BPD, current life, views of recovery, and experience of treatment and supports. Interviews were audio recorded, transcribed verbatim and entered into NVivo 11 for data analysis.

Interpretive phenomenological analysis (IPA) was used as the overarching methodology to understand individuals' experience and the ascribed meaning associated with the recovery journey in BPD [14]. Smaller sample sizes are recommended to gain in-depth understanding [14]. An inductive approach outlined by Smith and colleagues [14] was used to understand the emergent themes and the relationship between themes. Firstly, researchers immersed themselves in the narrative by reading transcripts, whilst free coding to gain an overarching understanding of the data. Secondly, free codes were coded into emergent themes summarising excerpts of individual's narratives. Emergent themes were then clustered into superordinate themes to describe individuals' experiences. This process was supported by discussions by the research team, where discrepancies between the team were resolved via consensus. Two transcripts, which represented over 10% of the data were coded by two independent raters (FN and CM) (inter-rater reliability = 91%). The remaining data was independently coded by one researcher (FN). The names of individuals have been de-identified to their participant number for

confidentiality purposes. Individuals in the recovered group are denoted with 'R' and those who are not recovered are denoted with 'NR'. Once the coding was determined by the researchers, the findings were discussed with a member of the consumer advisory committee, whose feedback was integrated to strengthen the paper (MJ).

Results

A total of 171 individuals provided contact details for follow-up from the online survey, where 108 individuals were contacted. Thirty-nine individuals completed the telephone interview. Using the study's inclusion criteria, 14 individual narratives (7 recovered and 7 not recovered) were included in the study. All individuals in this study were female with an average age of 33.36 years (SD = 10.26). The majority of individuals were from Australasia, with one individual from the Middle East. There were no significant differences on socio-demographic characteristics between the two groups. Comparison of socio-demographic characteristics of individuals are provided in Table 1.

Stages of recovery in borderline personality disorder

Recovery in BPD occurred across three core stages, including; 1) being stuck, 2) diagnosis, and 3) improving experience. Differences between individuals in the recovered and not recovered groups were observed in the final stage of recovery continuum. The movement between stages fluctuated, therefore narratives were discussed from a current or retrospective stance. A graphical representation of the stages and processes of recovery in BPD is depicted in Fig. 1.

Being stuck

This stage was characteristic of all individuals when first experiencing symptoms of BPD. Individuals did not have a clear conceptualisation of their experiences and described 'being stuck' as a state of *'floundering, getting bounced in and out of hospital… I was lacking in therapy and not really engaging in services'* (JTR191-R). An individual's emotional intensity was identified to impact upon daily living and was noted to extend beyond the realms of normal experience, where *'emotions are so raw and powerful, they drove everything. I had no insight whatsoever into what I was doing. I didn't know who I was, what I was doing or why. I reacted to everything in an unhealthy way'* (JTR280-R). Reports of maladaptive coping strategies such as self-harm or repeated suicide attempts were prevalent at this stage.

Negative experiences from childhood and adolescence, such as bullying or abuse, was reported to affect an individual's perception about self and others. For example *'BPD can be rooted in childhood trauma… I was taught it was always my fault as a child. Being in a relationship now with the same thing happen, my brain will assume, it is my fault'* (JTR051 – NR). The enduring nature was also noted in interpersonal difficulties, such that *'even at six years old, I had that instable personality… Not having any kind of self-worth and switching from one friend*

Table 1 Comparison of Socio-Demographic Participant Characteristics

Variable	Statistic	Total (*N* = 14)	Recovered Group (*n* = 7)	Not Recovered Group (*n* = 7)	t (p) or χ^2
Age	M (SD)	33.36 (10.26)	33.43 (11.43)	33.29 (9.88)	0.03 (0.98)
	Range	R = 18–52	R = 18–52	R = 22–46	
Education (years)	M (SD)	14.29 (1.94)	14.29 (2.29)	14.29 (1.70)	0.00 (1.00)
	Range	R = 11–16	R = 11–16	R = 11–16	
Employment status					
Engaged in paid work	% (n)	42.9 (6)	42.9 (3)	42.9 (3)	1.14 (0.57)
Relationship Status					
Single	% (n)	64.3 (9)	57.1 (4)	71.4 (5)	0.31 (0.58)
In relationship	% (n)	35.7 (5)	42.9 (3)	28.6 (2)	
Treatment Length (years)	M (SD)	12.68 (6.72)	9.93 (9.47)	15.43 (5.00)	−1.63 (0.13)
	Range	R = 2–24	R = 6–15	R = 9–21	
Age of Onset	M (SD)	9.71 (3.58)	10.57 (3.55)	8.86 (3.67)	−0.36 (0.73)
	Range	R = 4–15	R = 6–15	R = 4–14	
Age of Diagnosis	M (SD)	25.57 (10.14)	24.57 (9.47)	26.57 (11.44)	0.89 (0.39)
	Range	R = 15–45	R = 16–44	R = 15–45	
Gap between Onset and Diagnosis	M (SD)	15.86 (10.88)	14.00 (10.79)	17.71 (11.50)	−0.62 (0.55)
	Range	R = 6–38	R = 7–38	R = 6–34	

Note. No significant differences between recovered and not recovered groups

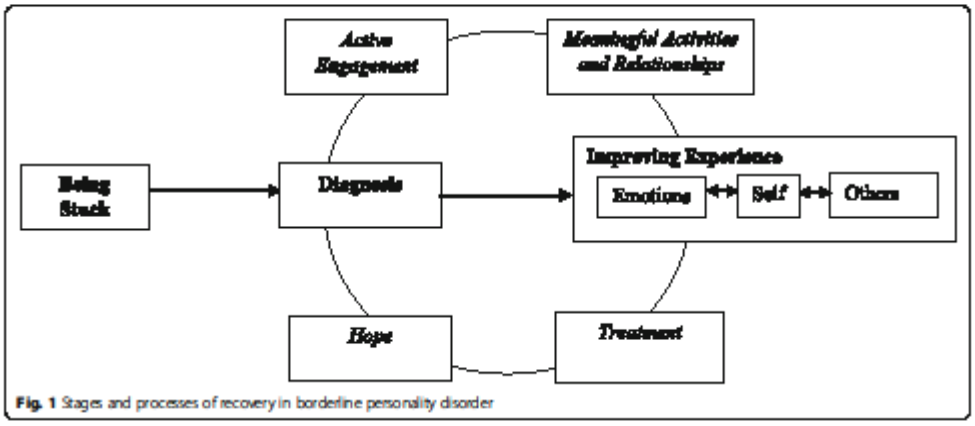

Fig. 1 Stages and processes of recovery in borderline personality disorder

to another depending on what my needs were and how that person was feeling…' (JTR239 – R).

Unsuccessful attempts at seeking help for mental health concerns was also characteristic during this stage. Misdiagnosis of other mental health concerns, such as depression, anxiety and bipolar disorder, were a common experience. Individuals reported these diagnoses did not encapsulate the severity of their experience, as *'it felt much worse but they told me my problems are mild and not an issue'* (JTR051 – NR). The knowledge of health professionals and the ability to access effective treatments were viewed to be crucial for an individual to move on from the 'being stuck' phase.

Diagnosis

Receiving a diagnosis of BPD was identified to be a turning point in assisting individuals to conceptualise their experiences and emotional intensity. Diagnosis provided individuals a narrative *'to describe what was going on, that I wasn't alone and other people had experienced this as well'* (JTR011 – R), giving individuals a sense of validation and relief, which assisted with progression in the recovery journey. The impact of delayed or mis-diagnosis was highlighted in the length of time taken to receive a diagnosis of BPD, as diagnosis assisted some individuals to gain access to evidence based treatment for BPD. Non-acceptance or disinterest in the diagnosis was reported by a minority of individuals, *'I didn't accept the borderline diagnosis. I wasn't interested and no one was interested in talking to me about it… but I understood what bipolar was and thought that did seem to fit'* (JTR239 – R). Some participants highlighted the immediate need for information about BPD to contextualise the diagnosis, as *'the worst thing is when people are not given any information when they are diagnosed with BPD.'* (JTR280 – R). Whilst knowledge was predominately acquired from engagement with health services, some individuals identified their own efforts to gain knowledge, *'I did a lot of reading once I got the diagnosis. It really made sense'* (JTR011 – R). However, the prevalence of stigma and discrimination associated with the diagnosis of BPD promoted negative experiences, where *'I've had some really traumatic experiences as a result of having the diagnosis… I no longer seek help if I'm in crisis, because I know that I'll get treated badly and be more stressed than if I didn't do anything…I feel like I don't trust the system'* (JTR051 – NR).

Improving experience

Developing greater awareness of emotions and of self and others was described as a core stage and influencer of recovery. Three domains were associated with this stage including 1) Developing Greater Awareness of Emotions and Thoughts, 2) Strengthening Sense of Self, and 3) Understanding the Perspectives of Others. These domains were not mutually exclusive, yet the progression made in this stage differed between individuals.

Individual's conceptualisation of recovery indicated that there was skepticism surrounding the amelioration of symptoms. Recovery was considered an ongoing journey with elements of survival, resilience and self-management. For example, *'it can be managed… I don't think the symptoms will ever 100% disappear forever. They'll always be there to some degree in the background. I hope I get to a point where it doesn't impact on your life in a negative way'* (JTR051 – NR). This was echoed by individuals who identified with being recovered as, *'I got to a point where I realised that all that suffering made me much stronger. I*

have more insight because I had to do the work to recover' (JTR280 – R).

Developing greater awareness of emotions and thoughts

The identification of emotions and thoughts was considered a starting point in fostering understanding of oneself and the use of coping strategies, such that *'I was beginning to develop more awareness of my emotions, but not so much control. Just the ability to not be blindsided by them'* (JTR459 – NR). However, the identification of emotions did not preclude individuals to distress, where *'I don't necessarily act on my thoughts anymore. My first reaction to something will be 'I should self-harm,' but even though I'm not actually physically doing it, having my thoughts consumed by it is distressing'* (JTR083 – NR).

Strengthening sense of self

All individuals acknowledged that developing one's sense of self was a central component of the recovery journey. Individuals who identified with being recovered provided greater details of the nuances of developing a stronger sense of self. This was conceptualised as a process of reframing how one understands or perceives oneself. This process was noted to commence in conjunction with developing skills to recognise and tolerate emotions.

Individual narratives discussed the lack of identity stemming from first experiences of BPD and their sense of self being constructed upon symptom experience and identification with the BPD diagnosis. For example; *'Sometimes I feel like my whole identity has been based around my trauma... and when you suddenly start being able to react differently to things, I kind of felt like a lot of my identity was disappearing, because I no longer feel as intense'* (JTR051 – NR). Stigma arising from interactions with others had the potential to reinforce negative self-perceptions, such that *'I was very reluctant to actually disclose to people [my diagnosis] up until only really a few years ago, because I disclosed previously without thinking about it and then experienced unpleasant responses.'* (JTR011 – R).

Being aware of individual patterns and triggers provided opportunities to *'always challenge myself to become better. Instead of avoiding things like I used to, I think about how I can do it until I'm not stressed out by it anymore'* (JTR233 – R). This allowed for skill practice but also a subsequent sense of agency. Difficulties moving away from the illness identity was articulated by a minority of individuals in the recovered group. Despite progress made in identifying emotions and skill usage, individuals noted that *'my therapist had been telling me that I was recovered and I didn't meet criteria, but I didn't believe her. I think it was because I lacked an identity. I still don't understand what identity is... I held onto that diagnosis for such a long time, that was who I was'* (JTR239 – R). The fear associated with developing a greater sense of self exacerbated this as *'what if I use the skills and do what I need to do to achieve recovery and I still hate myself?'* (JTR280 – R).

Understanding the perspectives of others

This theme was discussed by a minority of individuals in the recovered group. Individuals described this as a process of reflecting beyond one's own subjective experience to include the capacity of others and the relational context. The impact of being able to understand the perspectives of others in reconciling relationships was highlighted in an individual's response, where *'I got to experience the pain that I inflicted on my mother, by projecting all my self-loathing onto her. My mum had her own weaknesses... but I was too caught up in my own narcissistic injuries before to conceptualise how much pain I'd caused her.'* (JTR191 – R). This was similarly discussed by another individual, where the perspectives of others allowed for the calibration of her own perceptions of self. For example *'My husband always saw my potential and knew what I'm capable of, but I didn't see that at the time. I just thought he was ridiculous and was making fun of me, but I now know what he means'* (JTR072 – R).

Processes of recovery in borderline personality disorder

Four recovery processes in BPD were identified from individual's narratives; 1) active engagement in the recovery process, 2) hope, 3) treatment and, 4) meaningful activities and relationships. These processes could be overlapping and facilitate or hinder the recovery journey. Some differences between individuals in the recovered and not recovered groups were identified. These recovery processes contributed to the movement through the recovery stages and the growth within individuals.

Active engagement in the recovery process

The desire and willingness to engage in the recovery process was crucial for progress in recovery to be made. Yet these observations were often made from a retrospective standpoint, when individuals had already accepted their diagnosis and take *'responsibility to learn the skills and do it yourself, you're going to get to a finite point, where it's all going to be ok'* (JTR011 – R). Motivational differences between individuals in the recovered and not recovered groups were identified, such that individuals in the recovered group placed emphasis on intrinsic factors, whilst individuals in the not recovered group emphasised extrinsic factors. A minority of individuals identified that the mindset in which they approached treatment may impact on willingness to active engage in recovery such that a change-oriented

mindset was necessary. *'I was in treatment but I thought why I was sitting there listening to other people talk about their issues. I thought this isn't my problem and I felt so angry, I didn't see the point, so I dropped out.'* (JTR239 – R).

Hope

Hope was an overarching concept, permeated when experiences positively contrasted to individual perceptions or their worldview. Recovery was considered unexpected and promoted a new outlook which was not previously considered by some individuals. States of hopelessness particularly observed during the early stages was prevalent in all individuals, such that *'I didn't have any kind of hope. I didn't have anything to hold onto...'* (JTR239 – R). Hope could be generated through vocational and relational engagement and the subsequent sense of agency gained from the use of skills or reflection on progress. For some individuals in the not recovered group, the maintenance of hope was associated with the ability to get treatment, *'I had a wonderful psychologist who I got along really well with. But at the moment it's hard to keep my eye on the prize, per se'* (JTR459 - NR).

Hope played a role in the maintenance of motivation, as it contributed to gains in self-belief and the reduction of self-doubt. *'That sense of just knowing the emotions will end, this isn't a permanent thing... I used to feel like it was just never going to end'* (JTR239 – R). The shift in perspective had a compounding effect on individuals and their clinicians, as *'...I suppose I wouldn't expect it (recovery). I mean my clinicians were surprised by my recovery'* (JTR151 – R).

Engagement with treatment services

Seeking treatment was identified by all individuals as a key component in the recovery process, where effective treatment aligned with individual goals provided a sense of hope and the development of skills. Whilst these provided individuals a sense that *'this could be working. Maybe things will be ok'* (JTR061 – NR), services and treatments were described as mixed and fragmented. All individuals described at least one negative experience, where difficulties accessing treatment hindered progress on recovery. Individuals described greater difficulties when at the start of the recovery continuum.

Incongruent relationships through a lack of therapeutic alliance between clinician and individual also contributed to a lack of progress made in recovery, such that *'I don't think I progressed much with them (clinician) because we didn't fit well'* (JTR051 – NR). This contrasted to the progress made with clinicians who promoted collaborative and trustworthy relationships, as these fostered stronger relationships, as *'she would make an appointment with me and I wouldn't turn up. She didn't get angry... she just kept trying and waited until I was ready'* (JTR233 – R).

Engaging in meaningful activities and relationships

Engaging in meaningful activities and relationships was described as providing a sense of belonging and connectedness, the opportunity to practice new skills, reflect upon one's emotional reactions and sense of self. Although individual differences influenced what was considered meaningful, these commonly included employment, education, and relationships with friends, family, significant others and clinicians. Benefits such as the independence gained from being employed and the sense of *'affirmation and sense of purpose'* (JTR011-R) was discussed.

For some individuals during the early experiences of BPD, their experience of symptoms precluded their participation in activities such that when *'when I was a student and before I started working full-time, it was much harder and my symptoms were more pronounced. I had a lot more difficulty'* (JTR011-R). This also extended into the relational domain, where some individuals avoided relationships in fear of the negative effects on symptoms, such that *'I haven't had a relationship for the last seven months, it's easier when you don't have one... I'm really scared of actually going into a relationship again, because when that goes bad, I'm going to go bad.'* (JTR018 – NR).

All individuals acknowledged the role activities and relationships had for self-exploration and reflection. For example, meditation was described by one individual as *'a laboratory that helps you sit with yourself and watch how the emotions just rise and fall away'* (JTR191 – R). Whilst others identified differences in self in differing contexts, for example *'At work I would be fine, but I can be a complete mess outside of work. I can organise 10 other people but then my brain just switches. As soon as I don't have something to focus on, I focus on myself, which is bad.'* (JTR018 – NR). Noticing differences in oneself provided opportunities to gain greater insight into oneself.

Discussion

The present study aimed to gain a holistic understanding of recovery in individuals with lived experience of BPD at either end of the recovery continuum. Overall, recovery was characterised by an interaction between the stages and processes. The identification of recovery in BPD as an ongoing journey is reflective of current literature on personal recovery in mental health [2, 15].

The stages of recovery identified in the present study align with the broad recovery stages mapped by Leamy and colleagues [4]. However, stages identified were framed by individuals in a clinical manner. Domains

associated with improving experience were reflective of core psychopathology in BPD [16]. This mimics the tasks identified in other qualitative studies examining recovery in personality disorder [2, 6, 7]. Therefore, the developed framework may be reflective of recovery within the context of treatment. Individuals in this study on average had 10 years of treatment, therefore the importance of treatment as part of recovery is not without standing. Yet, the literature proposes that there are multiple routes to recovery, including engagement in non-traditional mental health services [3], The possibility of individual recovery through the use of other supports, such as peer workers or recovery colleges, could be further investigated within the context of personality disorder. Despite this, only the perspectives of women were included as part of the study. The perspectives of men could be a focus for future research.

As individuals were required to have a diagnosis of BPD to take part in the study, the being stuck and diagnosis stages were universally described. Diagnosis played a role in shifting the trajectory of experience and provide opportunity to formulate meaning and promote hope. However, the gap between an individual's perceived age of onset and age of diagnosis in this sample was approximately 15 years. This may be representative of a knowledge gap in health professionals and the need to upskill clinicians in working with people with personality disorder or stigma which may prevent timely diagnosis [7, 17, 18]. This compounds with the desire of individuals for information about BPD at diagnosis.

Differences between the recovered and not recovered groups were most pronounced in the improving experience stage. The narratives of individuals in the recovered group articulated experiences of understanding self and others, compared to individuals in the not recovered group who discussed working towards improving awareness of emotions and thoughts. Whilst growth is exemplified as a stage in other models of personal recovery, often involving self-management of symptoms [19], narratives in this study indicate that the process of growth began through gaining awareness of emotions.

Strengthening the sense of self was identified to be a domain central to growth. There are differences between what is currently conceptualised as identity in the personal recovery literature, which proposes that individuals reformulate their sense of self [20, 21], suggesting that individuals have some sense of self, prior to their first experiences of mental health concerns. In this study, individuals describe a lack of identity from first experiences of BPD. Adopting an illness identity has been associated with less favourable outcomes [22], whilst the movement away from illness identity is supported by the current personal recovery literature [4]. The emphasis on diagnosis in the current findings suggests that acceptance of the illness is required to a degree to progress in recovery in BPD. Over-identification however, can also lead to stagnation in recovery. Greater understanding of illness identity in BPD is required and is particularly salient given identity disturbances is core to the disorder. Identifying internal narratives may be a starting point in promoting motivation and willingness to engage in the recovery journey.

Engaging in relationships and meaningful activities is known to be a priority for individuals with BPD [1]. Interestingly, the proportion of individuals engaged in paid employment and in a relationship did not significantly differ, despite individuals being at either end of the recovery continuum. This indicates that recovery status may have an influence on the quality of the relationship or the amount of work engaged in. Existing longitudinal studies have identified that approximately 50% of individuals experience 'good recovery' following 10 years of follow-up, indicating that individuals have experienced concurrent remission from BPD and have full time vocational engagement [23, 24]. In the present study, less than half of the individuals in the recovered group were engaged in a relationship or in paid work, indicating that the current sample may have a more severe presentation and experience greater psychosocial difficulties compared participants in existing longitudinal studies. Differences between the treatment context in individuals in the current sample and longitudinal studies such as The McLean Study of Adult Development [24] are worth noting. Individuals in the McLean study were more functional and therefore likely to be employed than those in the current sample. This may be due to differences in capacity to pay for and access care, with the McLean sample being mainly health insured patients compared with our sample that were more reliant on stretched public services for care.

The broad recruitment strategy adopted by the study allowed for individuals to be recruited from more than one treatment service or service catchment, allowing for a wider range of views and experiences to be included in the study. However, consistent with previous research, the study adopted a retrospective approach. Difficulties in comparing individuals were encountered by researchers, as recovery is not a static process. For example, individuals in the not recovered group may have previously experienced periods in which they considered themselves as recovered and could draw on these experiences. The narratives of individuals may be subjected to some level of response bias given the significant gap between individual's age of onset, diagnosis and current age. The use of prospective longitudinal research to map recovery to obtain real time accounts may be a direction for future research. The adoption of blind data

collection and analysis process may also reduce the likelihood of researcher bias.

Conclusion

This study identified stages and processes associated with recovery in BPD through the perspectives of individuals with lived experience. The findings extend existing knowledge by contrasting the experiences of individuals at either ends of the recovery continuum. The inclusion of individuals in the recovered group, provides a stronger indication of what the full recovery spectrum may constitute. The findings however, represents recovery in the context of treatment. Therefore, it is difficult to extend these findings to individuals who seek support for BPD outside of traditional treatment services. To incorporate a more holistic approach to recovery in clinical practice, it is recommended that a greater focus on individual motivation, treatment engagement, relationships and hope is needed.

Additional file

Additional file 1: Interview Schedule. (DOCX 15 kb)

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Availability of data and materials
Data from the current study will not be made available, as participants did not consent for their transcripts to be publically released. Extracts of participant responses have been made available within the manuscript.

Authors' contributions
FYYN designed the study, recruited participants, conducted all interview participants, conducted the formal data analysis, and wrote the first draft of the manuscript. MLT contributed to the interpretation of the results. CM was the secondary coder for qualitative data analysis. MI contributed to the interpretation of the results. BFSG contributed to the design of the study and interpretation of the results. All authors read and approved the final version of the manuscript.

Ethics approval and consent to participate
This study received ethics approval prior to the start of the study from the University of Wollongong Social Sciences Human Research Ethics Committee (HE16/215). All participants were informed of the aims and risks of the study and provided informed consent.

Consent for publication
Not applicable.

Competing interests
The authors have no competing interests to declare.

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APPENDIX P: Additional Illustrative Quotes from Phase Four

Superordinate Theme	Sub-theme	Representative Quotes
Stages of Recovery	Being Stuck	'It started off with depression and anxiety. I've had anxiety for as long as I can remember; I just didn't know that that's what it was, so through my childhood I was in, kind of, constant fear of my mum. I was always on high alert and the anxiety was just the normal level for me and then I think because I'd been anxious for so long I started getting depressed. So I was focused more on that and then probably with that then more trouble around the identity stuff and not knowing who I was and always questioning, that sort of thing.' (JTR072 – R) 'I think within myself it's the fight that I keep fighting at the moment it's choosing to live every day. It's exhausting and it takes up a lot of my time and at the moment I guess finding a reason every day to do more it's really every day finding a reason to stay alive and to live another day and to make choices not to harm myself. Even now I struggle and, um, I've had a fair few episodes where I've self-harmed recently. And

		when, when every part of you is screaming to just give up and there's that part of you that just, there's this small part of you that says, no you've got to keep fighting.' (JTR061 – NR) 'I actually think about two years old when initial symptoms started coming through, which sounds really, really young. Because that's sort of when the abuse started and I was constantly feeling like, oh, everything is my fault. So I sort of found that I would I felt guilty about things that I didn't do. I think back on the years when I was young from two, three, four upwards, my dad would be like, "Well, you did this." And I'd be like, "Oh, okay." So, that kind of ingrained in me to sort of automatically assume everything bad was my fault… And just remember being quite angry from a very young age. Like, yeah, then I think, um, when I hit, sort of, nine, I started having suicidal thoughts for the first time.' (JTR051 – NR) 'When I was about five, would have been when my anxiety started. But that was horrid. And then it kind of progressed to suicidal thoughts when I was nine or 10. I think I would have been 11 or 12 by the first time I really wanted to actually try. And found mega pills

		and everything and I was reading up on it too and just thank God Google wasn't around back then, because it was more like you're reading fiction books to, sort of figure it out, there were just silly stories and stuff and then you'd try and figure out if they were scientifically doable or not. After my first one, they just basically just pumped me up with more pills and everything. And there was no support there. The hospital was pretty terrible too and it was pretty horrible.' (JTR018- NR)
	Diagnosis	'I was very, very reluctant to actually disclose to people up until only really a few years ago, because I really just wasn't prepared to. I disclosed previously, without thinking about it and then experienced really unpleasant responses from people.' (JTR011 – R) 'I didn't accept the Borderline diagnosis. I just sort of threw it away. I wasn't interested. No one was interested in talking to me about it. Nobody knew what it was. It was basically just like nothing so because I understood what Bipolar was and I thought, well, yeah, this - this does seem to fit. It wasn't until when I was 26 and I was thinking about suicide again and, because I had been suicidal for many years, I just hadn't attempted it, but I was thinking about wanting to attempt it again. And I was like, okay, what is this

		Borderline, what does it mean, and then as soon as I read it I was just like, oh my gosh, this is what has been happening to me for all these years. I really identified with it and it was then I went and got re-diagnosed and they said, "Yeah, you're not - you don't have Bipolar. This is definitely what's going on."' (JTR239 – R) 'I had been seeing my psychiatrist who had been treating me with cognitive behavioural therapy just for depression but my GP felt that there was more going on and so he sent me to a hospital for help. I had a full day with them and they came back with the diagnosis of borderline. Unfortunately my GP at the time didn't really know what borderline was and he thought it was a type of bipolar and so that's how he treated me, as having bipolar. He didn't understand what borderline was. So I went for a long time thinking I had a type of bipolar.' (JTR022 – NR) 'I was always told, "Oh, you have a mild depression" and I always felt like it feels much worse… And I felt like, they were kind of telling me, oh, your problems are really just mild and they are not an issue… I was quite relieved to have a diagnosis. I felt kind of

		validated, not that I was hell-bent on the diagnosis but I was constantly being invalidated by the fact it was just a general mild depression' (JTR051 – NR) 'There is a massive stigma. And it's still real and it's still very much out there. I've had some really traumatic experiences as a result of having the diagnosis. And they would ignore any other diagnosis… as soon as they hear the word BPD, or that you have BPD, they would suddenly treat me like I was an animal. I think I struggled for a long time, and I still do, with having professionals know. I no longer seek help if I'm in crisis. I don't ring health lines, I don't tell people, because I know that I'll get treated really badly, and I end up being more stressed than if I didn't do anything.' (JTR051 – NR).
	Improving Experience	**Emotions** 'I am at least recognising the triggers before I fall into them.' (JTR018 – NR) 'Obviously I still struggle sometimes, but comparatively it's a bit easier for me to sort of automatically say I'm feeling this emotion, and I'll try and re-phrase it. So, now that I can usually identify what I'm feeling, which I never used to be able to. I would just feel

		overwhelmed, and I wasn't really sure if it was anger, sadness or whatever. Now that I kind of know a bit better how to identify what the root feeling is, I can better deal with that emotion. So, if I am sad as opposed to angry, like, I might just think I'm angry because I'm overwhelmed, if I realise I'm actually sad, I can sort of tailor my self-care to that emotion.' (JTR051 – NR) 'I recognise it more quickly, I mean for triggers and abandonment. They come up in, like, my personal relationship, like with my husband. So it could be something really simple, if he just didn't listen to me while I was talking to him, which I do all the time to him but and so I automatically recognise that I'm feeling that way.' (JTR072 – R) **Self** 'One of the things that's become very important to me over time and it's around sort of being self-aware, is mindfulness. Just around being aware of what's going on for me and trying to also be mindful of what's going on around me. I used to kind of really rush into things and make decisions really quickly. And now I tend to be much more

		considered. I actually think that that's a skill that I've had to develop over time.' (JTR011 – R). 'When you tend to be a little bit emotionally fragile or malleable, it's very easy for people to be manipulative. Actually owning and feeling that it's okay to be able to say, no, this is what my need is and you need to respect my need and boundary, because sometimes people aren't respectful of them… I have recognised that some people do respect your boundaries and then I've learnt a lot about how to set emotional boundaries and ones that I'm comfortable with. Being able to set boundaries has then allowed me the space to be able to say, well, that people is not really right for me' (JTR011 – R). 'I found myself going back to my job service provider and saying, "I'm really unable to do this 15 hours a week. Fifteen hours is unmanageable for me, um, at the moment." So I mean it's hard to know my limits, even though I really want to be well and be able to do more, but the reality is that with where I'm at with my head space at the moment and with the medications that I'm on, I'm just not able to at the moment.' (JTR061- NR)

		‘I’m learning more about myself. I’m just learning who I am, what I want, my barriers and I am actually able to work towards a life I want.’ (JTR151-R) **Other** ‘I also got to experience, which I needed to, um, the pain that I have inflicted on my mother, by projecting all my self-loathing onto her. My mum, obviously, has her own weaknesses… but I was too caught in my own like narcissistic injuries before then, to really, um, conceptualise how much pain I'd caused her.’ (JTR191 – R) ‘…even down to the way a person looks. If I was bullied or something by a person who even looked remotely like this new person, I used to in the past attach those sort of feelings towards that, like they would be that person to me. I don't do that anymore because I'm just like, well, no, they're not that person. They're a completely different person and so I'm finding that I'm able to have relationships with people who in the past I would just instantly dismiss because of the way they looked or maybe things that I might have thought about them which I had no basis to think.’ (JTR239 – R)

Processes of Recovery	**Active Engagement**	‘In recovery, I got to a point where I realised that all that suffering made me so much stronger, and I have more insight than most other people, because I had to do that work to recover. I see things that other people don’t see, so there’s actually a purpose in the trauma but it doesn’t make it any easier. I would never go through it again but there is a positive to it happening, because I can now share insights with people that most people don’t see’ (JTR280 – R) ‘What I do is, using DBT skills which I learnt, I work my hardest to keep myself above a certain level so that I can get right back out of it as soon as it’s over. I still think that I can, I can go back to it if I don’t try to keep myself in a stable place.’ (JTR151 – R) ‘It's just about always working to better yourself. Just always challenging myself to become better. If I find that this one thing really stresses me out then instead of avoiding it like I used to I will, you know, think about how I can do it until I'm not stressed out by it anymore. Just learning about yourself all the time, learning to accept yourself, learning

		the things you don't like yourself. If you can change them, work on changing them.' (JTR233 – R) 'I've struggled with just attending normal psychology appointments. With DBT, I know it's probably going to be a struggle as well when I actually do find a proper program to do. Self-responsibility comes along with self-determination, though. I mean pretty much being able to take part in something and actually be involved, instead of, instead of being merely practised upon. Like actually being involved in the recovery process, to such a point that you've got to walk that journey, and someone is walking alongside you, not leading you. Or dragging you.' (JTR459 – NR)
	Meaningful Activities and Relationships	'I am employed… I still do love it, but I used to love it so much that it was my only escape from any of my stresses. I always thought it was good before that it was, kind of, my escape from stress, because, like, the doctor just said, I'm high functioning, so at work I'm fine. It's really confusing, because I can be a complete mess; I can turn around and go into work; I can do 10 things at once and organise 10 other people and then come

		home and my brain just switches again and, you know, although, you know, as soon as I don't have something to focus on I focus on me, which is really bad.' (JTR018 – NR) 'I actually was in recovery for a while and I actually did reach a point where the borderline wasn't impacting on my life. I had 12 months of what I call normal life where I was able to hold down a very stressful job, my marriage was doing really well, I had a social life. I had, um, all the things that are considered normal I suppose. I don't work in a job now however, but I am what's called a home hobbyist.' (JTR022 – NR) 'I haven't had a relationship for the last seven months and it's always easier when you don't have one. I don't have as much stuff to stuff up, I guess where I get really emotional and stuff. I'm really scared of actually going into a relationship again, because I'm scared that when that goes bad then I know I'm going to go bad. I just want to try and get as well as I can before that to just hopefully it's not going to be as bad next time or maybe I just can't do it or something. I've been lucky because I haven't had that relationship

		thing, it – which is where I would really slip back into it, um, really easily and really badly.' (JTR018 – NR)
	Hope	'I can feel myself progressing, but a year ago I thought, you know, I know there's absolutely no way you can recover. But I, sort of, feel like there is that little bit of hope where maybe, I don't think I would be a hundred per cent, but I feel hopeful. I've never felt hopeful before. I've always just thought, you know, I'll give it a try and whatever, but I've never actually felt hopeful and now I do.' (JTR018 – NR) 'I've honestly thought I was going to break so many times, throughout the course of my life. And whether or not I have broken, I haven't broken completely. I can say that. I mean it could have caused more knocks, and dings, and dents, and, and scars, but I'm still here.' (JTR459 – NR) 'I think probably not thinking the same ways as I used to. Knowing that things will be better tomorrow or just knowing that things will be better and not feeling perpetually stuck, having that sense of just knowing that the emotions will end, this isn't a permanent

		thing, because I think that's the biggest thing for me. I used to feel like it was just never going to end, like I couldn't see where it would end.' (JTR239 – R) 'I think to a certain degree there's hope. BPD is kind of like on a continuum of people. We're more sensitive to less sensitive. It's obviously a part of my personality.' (JTR151 – R)
	Treatment	'The other thing would be finding the help to start with… Actually that's probably the biggest thing, because I haven't, um, like, I'm really surprised I got out of this rut. The last time I went to hospital, I was told I was going to get all this support. I was supposed to have been put on this waiting list for DBT. I was supposed to get, you know, people call me and check up on me. I did have the mental health assistance line it was really amazing.' (JTR018 – NR) 'I have this fear of abandonment and people leaving. The therapeutic relationship obviously don't last forever, so it's been really hard to reconnect. It takes a lot of time

		to kind of develop that kind of therapeutic relationship and it definitely is quite difficult especially when someone leaves.' (JTR061 – NR) 'I trusted my psychologist, she said this might be helpful and I was like I've got to do things. I'm not great at, um, requesting help. That's probably still something I find it difficult to ask others for help.' (JTR072 – R). 'I started seeing a therapist and she was a DBT therapist but she wasn't able to help me in the same ways that I found help in a different therapist. I saw her for six months and I attended the group at that point, but I just couldn't wrap my head around it. I went to the group and I remember thinking, and it was my first session and they were doing homework and I was so confused by what the skills were and why they were going to help me and it seemed really, for lack of a better word, it seemed kind of just wishy-washy. But then, six months later I was seeing a different therapist, um, and to this day she is still the one I see. She made the difference.' (JTR239 – R)